

DOCUMENT RESUME

ED 143 157

EC 101 397

AUTHOR Gollay, Elinor
TITLE A Study of the Community Adjustment of
Deinstitutionalized Mentally Retarded Persons. Volume
V. An Analysis of Factors Associated with Community
Adjustment.
INSTITUTION Abt Associates, Inc. Cambridge, Mass.
SPONS AGENCY Bureau of Education for the Handicapped (DHEW/OE),
Washington, D.C.
REPORT NO AAI-76-225
PUB DATE Dec 76
CONTRACT OEC-0-74-9183
NOTE 82p.; For related information, see EC 101 393-398
EDRS PRICE MF-\$0.83 HC-\$4.67 Plus Postage.
DESCRIPTORS *Adjustment (to Environment); *Community Resources;
Community Role; Exceptional Child Research;
Institutionalized Persons; *Mentally Handicapped;
Normalization (Handicapped)
IDENTIFIERS *Deinstitutionalization

ABSTRACT

Presented in the fifth of a six volume series is an analysis of 25 variables associated with aspects of community adjustment for 440 deinstitutionalized mentally retarded persons. The first section deals with such research methodology aspects as instrument design and data gathering. The second section contains a profile of outcome and predictor variables (individual characteristics, institutional experiences, institutional characteristics, and community characteristics). Differences in variables according to level of retardation and age of Ss are described in the third section. Section four portrays the correlations among major categories of variables, and section five presents the results of step-wise regressions using the five outcome variables: returning to the institution, overall activity level in the community, unmet needs in the community, and independence of residential setting in the community. Among the conclusions listed in the sixth section are that a person's age, level of retardation, and involvement in institutional activities prior to release have a direct affect on post-institutional adjustment. (CL)

* Documents acquired by ERIC include many informal unpublished *
* materials not available from other sources. ERIC makes every effort *
* to obtain the best copy available. Nevertheless, items of marginal *
* reproducibility are often encountered and this affects the quality *
* of the microfiche and hardcopy reproductions ERIC makes available *
* via the ERIC Document Reproduction Service (EDRS). EDRS is not *
* responsible for the quality of the original document. Reproductions *
* supplied by EDRS are the best that can be made from the original. *

ED143157

ABT ASSOCIATES INC.
55 WHEELER STREET, CAMBRIDGE, MASSACHUSETTS 02138
TELEPHONE • AREA 617-492-7100
TELEX: 710-320-8367

Report No. AAI-76-225

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Contract No. OEC-0-74-9183

AN ANALYSIS OF FACTORS
ASSOCIATED WITH COMMUNITY ADJUSTMENT

December, 1976

Principal Author:

Elinor Gollay

Volume V of:

A Study of the Community Adjustment
of Deinstitutionalized Mentally Retarded Persons

Elinor Gollay, Project Director

Ruth Freedman, Deputy Project Director

Prepared for:

U.S. OFFICE OF EDUCATION
Bureau of Education for the Handicapped
Washington, D.C. 20202

EC 101397

<i>Elinor Gollay</i> Contract Manager	<i>Wm H/S</i> Quality Control Reviewer	<i>[Signature]</i> Management Reviewer
--	---	---

ACKNOWLEDGEMENTS

In July, 1974, Abt Associates was awarded a contract by the Bureau of Education for the Handicapped of the United States Office of Education to conduct an assessment of the adjustment of deinstitutionalized mentally retarded people to community life (Contract No. OEC-O-74-9183). The present volume is one of a six-volume series produced over the course of the project to describe deinstitutionalization procedures of institutions and community adjustment experiences of mentally retarded persons. We are deeply indebted to many people for their cooperation and assistance in all phases of this project.

First, we wish to give special thanks to our Project Officer in the United States Office of Education's Bureau of Education for the Handicapped, William Johnston, for providing support and guidance to us throughout the course of the contract, and to Max Mueller, Chief, Research Division, BEH.

The Abt Associates research staff who assisted in this project worked long and difficult hours to prepare, analyze, and report the data in these volumes. First, we wish to thank Patricia Cook, who served as the Project Director of this study from July, 1974 to May, 1975. Special thanks go to Diane Stoner, Supervisor of Field Operations, and to Jaime Grubin and coders from the Survey Design Group for pre-coding our instruments and subsequently coding the data; to Joe Clark, Sandy Friedman, and Paul Robertson for their invaluable help in preparing the complex data base and carrying out the computer work; to Jim Hoell and Karen Schneiderman for helping organize the data into meaningful tables and charts; and to Kathy Moss and Paul Robertson for assistance in writing up our findings.

We are expecially grateful to Professor Norman R. Kurtz of the Florence Heller School for Advanced Studies in Social Welfare, who served as an on-going consultant on this project. He was helpful in various phases of the project, particularly in reviewing our instruments, developing and carrying out our analysis plan, and reviewing our working documents.

Corporate staff at Abt Associates who deserve thanks for their support and guidance are Andy Anderson, our contract management reviewer, and Peter Miller, Education Area Manager and Vice President.

The study involved two major field efforts: 1) visits and interviews by field staff at 10 selected institutions serving mentally retarded persons; and 2) visits and interviews by field staff with the 440 deinstitutionalized clients and their families. The field staff worked enthusiastically and effectively in collecting the data, sometimes under difficult field conditions and time constraints. We wish to thank the field staff who conducted the site visits to the ten institutions--Marjorie Scarlett, Laurie Stewart, and Bonnie Wilpon--as well as the staff who conducted interviews with deinstitutionalized clients and their families--Sharon Alperin, Joel Braun, Amy Cicala, Michael Clifford, Barbara Epstein, Eleanor Franklin, Lois Gerardi, Ellen Hartford, Lauri Lewis, Vicki Peters, John Schlichte, Suzanne Simenson, and Jan Valley.

Special thanks go to the Mohawks and Squaws, a consultant group of mentally retarded persons, and to Adrienne Glenn in particular, who helped sensitize and train our field staff to the process of interviewing mentally retarded persons. We are also grateful to the institutions and persons who assisted us in pre-testing instruments and questionnaires--particularly the staff at Monson State School, Monson, Massachusetts, and the staff at Seaside Regional Center, Waterford, Connecticut, and the host of families, group home staff, and deinstitutionalized clients.

We wish to thank the 154 institutions which responded to our initial mail survey and particularly the staff at the 10 institutions participating in this study. Participation required a great deal of time and effort on their part, with little promise of returns which could directly benefit them. Their motivation for participating was based on a desire to assist in a research project which they felt was greatly needed. We hope that our study reports meet their expectations and will be helpful in preparing training programs and placing clients in community settings. The institutions participating were:

Arlington Development Center
Arlington, Tennessee

Beatrice State Home
Beatrice, Nebraska

Belchertown State School
Belchertown, Massachusetts

Brainerd State Hospital
Brainerd, Minnesota

Brandon Training School
Brandon, Vermont

Northern Wisconsin Colony and Training School
Chippewa Falls, Wisconsin

Polk State School and Hospital
Polk, Pennsylvania

Suffolk Developmental Center
Suffolk, New York

Sunland at Tallahassee
Tallahassee, Florida

Utah State Training School
American Fork, Utah

Above all, our praise and thanks go to the 440 deinstitutionalized clients and their families who participated in this study. They spent long hours with our interviewers providing difficult information on community adjustment experiences. As with the participating institutions, there were no direct benefits to them for participating in the study. Without their efforts and insights, a report such as this could not have been written. We can only hope that the findings and recommendations of this study might facilitate the community adjustment of persons who are released from institutions in the future.

Elinor Gollay, Project Director
Ruth Friedman, Deputy Project Director
Marty Wyngaarden, Research Analyst

PREFACE: PROJECT OVERVIEW

Objectives

This report is based on a study conducted by Abt Associates Inc. for the Bureau of Education for the Handicapped of the United States Office of Education (Contract No. OEC-0-74-9183). The overall purpose is to assess the adjustment of deinstitutionalized mentally retarded people to community life. The objectives are six-fold:

1. to review the criterion measures and predictors of community adjustment used in studies of mentally retarded persons and to analyze the research issues related to these projects. The findings of this review are contained in Volume I: Approaches to Defining and Measuring the Community Adjustment of Mentally Retarded Persons--A Review of the Literature.
2. to describe the current patterns of deinstitutionalization based on a mail survey of 250 institutions across the nation involved in deinstitutionalizing mentally retarded persons. Volume II: Profile of National Deinstitutionalization Patterns 1972-1974 summarizes the findings of this survey.
3. to describe the deinstitutionalization procedures and policies of 10 selected residential institutions serving mentally retarded persons based on field visits made to these facilities by project staff. The findings of these visits are published in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People.
4. to describe the community experiences of mentally retarded persons, based on interviews with 440 clients (released from the selected institutions described in objective 3) and their "families" (e.g., parents, foster parents, guardians, or whoever was providing care and supervision for the client in the community setting). This descriptive data is presented in Volume IV: Descriptive Data on the Community Experiences of Mentally Retarded Persons.
5. to determine what institutional, client, and community factors contribute to successful community adjustment based on the interviews described in objective 4 and on institutional data collected during the field visits to the ten institutions. Volume V: An Analysis of Factors Contributing to Community Adjustment presents the findings of this analysis.
6. to summarize the findings of the previous 5 volumes and to provide recommendations to USOE for further research related to deinstitutionalization based on the analysis of the data collected according to the objectives described above. These findings are published in Volume VI: Executive Summary--Overall Findings and Recommendations.

Overall Research Design

The overall research design employed in this study is depicted graphically in Table A. As can be seen from the table, there were four major phases to the study design: 1) conceptualization; 2) instrument design; 3) data collection; and 4) analysis and report writing. The findings reported in Volumes 1-6 were based upon the procedures undertaken in each of the four phases. In order to present an overall picture of the research design, the phases will be briefly described in this section. More detailed information on these phases as they relate to each of the specific volumes is presented in the "Methodology" section of each of the first five volumes.

Conceptualization

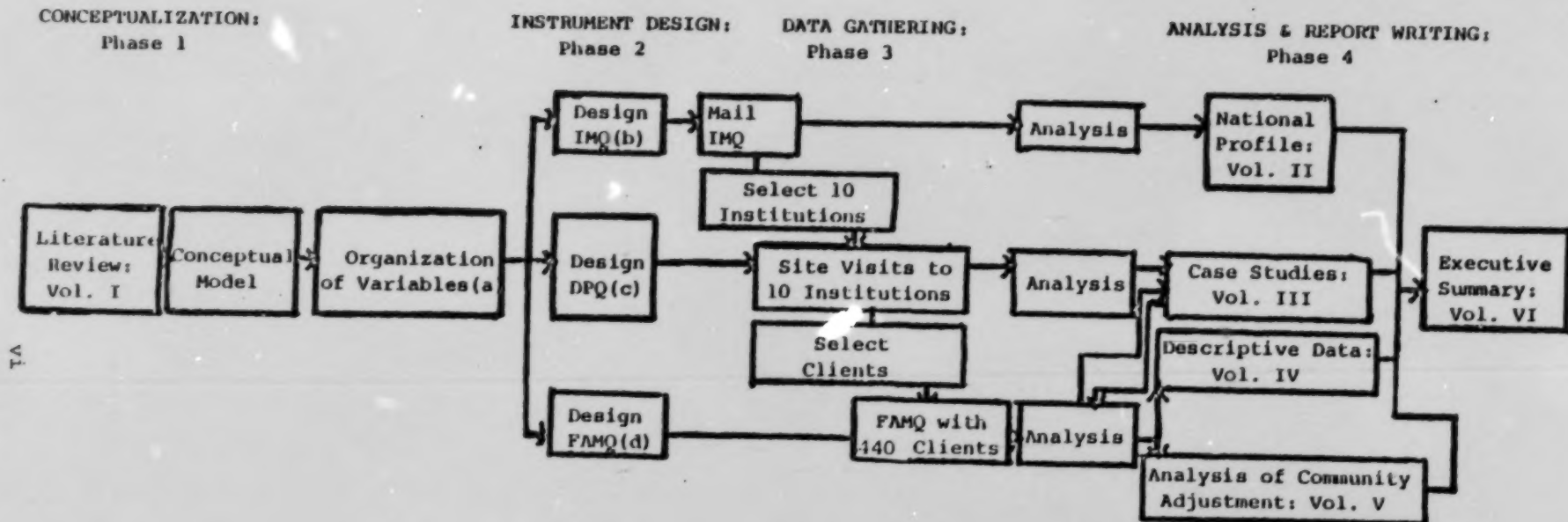
The first major phase involved developing a conceptual model of deinstitutionalization and the community adjustment process. First, a review of the literature was conducted. Based on the findings of this review (reported in Volume I), a model was developed setting forth the study's assumptions about the process of deinstitutionalization and community adjustment. The model included nine sets of variables which encompassed the major characteristics of deinstitutionalization and the community adjustment experiences. The nine sets of variables are listed at the bottom of Table A (see "a" in Table A). More specific information on the content of these variables and their role as independent and dependent measures is contained in the "Methodology" section of each of the first five volumes.

Instrument Design

Three groups of instruments were designed to collect data on the nine variable sets:

1. Institutional Mail Questionnaire (IMQ) -- a mail questionnaire designed to obtain information on the deinstitutionalization procedures and release patterns of 250 institutions across the nation serving mentally retarded clients.
2. Deinstitutionalization Procedures Questionnaire (DPQ) -- a questionnaire designed to survey ten institutions selected for in-depth case study descriptions regarding deinstitutionalization and pre-release policies, procedures and programs.

TABLE A.

OVERALL RESEARCH DESIGN.(a) Sets of Variables

Client Characteristics
 Institutional Characteristics
 Community Characteristics
 Residential Characteristics
 Day Activity Experiences
 Residential Experiences
 Services and Training
 Social & Civic Activities
 Problems & Interpersonal Relationships

(b) IMQ Data Areas

Residential Population
 Release Patterns
 Pre-Release/Post-Release Services
 Institutional Clearance
 Procedures for Study

(c) DPQ Data Areas

State Policies/Legislation
 Client Assessment Procedures
 Pre-Release Programs
 Release Procedures
 Follow-Up Procedures and Support

(d) FAMQ Data Areas

Interview with Client
 Interview with Family
 Adaptive Behavior Scale
 Client Data Recording Form
 Final Comments Sheet

3. "Family" Questionnaires (FAMQ) -- a series of instruments designed to obtain data on the community adjustment experiences of deinstitutionalized clients living in the community. The types of instruments included in the Family Questionnaire are listed at the bottom of Table A (see "d" in Table A). The instruments included an interview questionnaire to be administered to the deinstitutionalized client; a questionnaire administered to the client's family; an Adaptive Behavior Checklist (ABS) measuring the functional level of the client; a Client Data Recording Form (CDRF) obtaining demographic data from institutional records about the client (e.g., age, number of years institutionalized, date of discharge, etc.); and a Final Comments Sheet (FCS) to record the interviewer's impressions.

Data Gathering

The three sets of instruments described above were administered to the appropriate respondents in a sequential fashion. First, the IMQ was mailed to 250 institutions serving mentally retarded persons across the nation. Ten institutions were selected for in-depth case study descriptions (see "Methodology" sections of volumes for description of selection procedures used for IMQ respondents). The 10 institutions were then visited by project staff to collect data using the DPQ. Based on the data and on further contact with institutional staff, 440 deinstitutionalized clients released from their institutions were selected for study. (See "Methodology" section of volumes for descriptions of these selection procedures.) Finally, the FAMQ series of instruments was used to gather data on study group clients.

Analysis and Report Writing

The data described above were analyzed and reported in several ways. The findings based on IMQ data are reported in Volume II: Profile of National Deinstitutionalization Patterns, 1972-1974. The data obtained from the DPQ were analyzed in two ways: 1) case study descriptions of the individual institutions and a cross-case study summary which is reported in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People; and 2) portions of the DPQ data served as independent variables for the analysis reported in Volume V: An Analysis of Factors Contributing to Community Adjustment. Similarly, the FAMQ data were analyzed in several ways: 1) data on the community experience of clients in the study group are reported descriptively in Volume IV: Descriptive Data on the Community Experiences of Mentally

Retarded Persons and also in the final chapter of each institution's case study description in Volume III; 2) FAMQ data are organized into independent and dependent measures of community adjustment and reported in Volume V: An Analysis of Factors Contributing to Community Adjustment. All of the data collected and reported in Volumes 1-5 were then analyzed in terms of their implications for overall study findings and recommendations. These overall findings and recommendations are reported in this report, Volume VI: Executive Summary.

Organization of This Volume

This volume presents the analysis of a final set of approximately 25 variables to determine which variables are associated with different aspects of "community adjustment." These final variables are divided into two main groups and a total of five groups altogether: predictor variables (individual characteristics, institutional experiences, institutional characteristics, community characteristics) and outcome variables. The presentation of the data is divided into the following sections: Section 2.0 is the distribution of the final set of variables. This section provides a profile of how the total sample of 440 is distributed according to the final set of "predictor" and "outcome" variables and some of the component variables that were used to create these final variables. Section 3.0 presents the differences which exist within the total sample on the final variables according to the level of retardation of the study group members, and according to the age of the study group members. These differences were determined through analyses of variances using age and level of retardation as the independent variables. Section 4.0 presents the correlations among the major categories of variables used in the analysis. Section 5.0 presents the results of five step-wise regressions which were performed using the five outcome variables: returning to the institution, overall activity level in the community, unmet needs in the community, problems in the community, and independence of residential setting in the community. Section 6.0 is the summary of the findings from the volume.

TABLE OF CONTENTS

	Page
1.0 INTRODUCTION: METHODOLOGY	1
1.1 Conceptualization	1
1.1.1 Introduction	1
1.1.2 Study's Assumptions Regarding Deinstitutionalization and Community Adjustment	1
1.1.3 Organization of Variables	2
1.1.4 Limitations	3
1.2 Instrument Design	4
1.2.1 Design of the Institutional Mail Questionnaire (IMQ)	4
1.2.2 Design of the Deinstitutionalization Procedures Questionnaire (DPQ)	5
1.2.3 Design of the Family Questionnaire (FAMQ)	8
1.3 Study Group Selection	11
1.3.1 Selection of Respondents for IMQ	11
1.3.2 Selection of Ten Institutions for DPQ	12
1.3.3 Selection of Deinstitutionalized Clients for FAMQ	13
1.4 Data Gathering	17
1.4.1 IMQ Data Gathering	17
1.4.2 DPQ Data Gathering	17
1.4.3 FAMQ Data Gathering	19
1.5 Data Analysis and Reporting	22
1.6 Steps Used in the Analysis	25
2.0 DISTRIBUTION OF THE FINAL VARIABLES	32
2.1 Outcome Variables	32
2.2 Predictor Variables	36
2.2.1 Individual Characteristics	36
2.2.2 Institutional Experiences	37
2.2.3 Institutional Characteristics	39
2.2.4 Community Characteristics	42
3.0 ANALYSIS OF VARIANCE (ANOVA) RESULTS	45
3.1 Differences According to Client Age	45
3.2 Differences According to Level of Retardation	48

	Page
4.0 CORRELATIONS AMONG THE FINAL VARIABLES	51
4.1 Correlations within Groups	51
4.2 Correlations Among the Groups of Variables	52
4.3 Correlations between Community Experiences (Outcome Variables) and Other Variables	55
5.0 RESULTS OF THE STEP-WISE REGRESSIONS	58
5.1 Returning to the Institution/ Remaining in the Community	58
5.2 Total Activity Level	61
5.3 Problems	61
5.4 Independence in the Living Setting	62
5.5 Unmet Need	63
5.6 Individual Characteristics	64
5.7 Institutional Experiences	64
5.8 Institutional Characteristics	65
5.9 Community Characteristics	66
5.10 Community Experiences	66
6.0 SUMMARY	67

1.0 INTRODUCTION: METHODOLOGY

1.1 Conceptualization

1.1.1 Introduction

A conceptual model for assessing the community adjustment of de-institutionalized clients was developed through a lengthy process. First, the literature was reviewed for previous work in this area. (See Volume I for the findings of this review.) Persons currently conducting similar research were contacted by telephone or in person and asked to describe their projects. Materials obtained from these sources were then reviewed for relevance to this study.

Based on the above steps and on the practical experience and knowledge of Abt staff and consultants about the deinstitutionalization process, staff identified the major research question of this study:

What are the major institutional, community, and client variables which contribute to the successful adjustment of deinstitutionalized mentally retarded people to community life?

A conceptual model of community adjustment was then developed to address the research question stated above. The purpose of the model was to set forth the study's assumptions about the process of deinstitutionalization and community adjustment, and to help organize the sets of dependent and independent variables around which the instrument design, data collection, and data analysis were organized.

1.1.2 Study's Assumptions Regarding Deinstitutionalization and Community Adjustment

One of the major findings of the literature review was that the terms "deinstitutionalization" and "community adjustment" have been widely used, connoting different meanings and values in various contexts. It was therefore essential to clarify the meanings of these terms and their use in the study's conceptual model.

Deinstitutionalization has traditionally referred to the preparation for and release of institutionalized persons into community settings. For the purposes of this study, deinstitutionalization is defined as the placement of mentally retarded people in community settings following their enrollment in residential institutions (facilities serving over 100 handicapped

clients) for two or more consecutive years. "Community placements" or settings include natural homes, foster homes, group homes, and semi-independent as well as independent living units. In this study, community placements did not include residential settings which were restrictive or as sheltered as the institutions from which clients were released (e.g., nursing homes, state schools, and state hospitals), nor residential settings serving over 100 persons. In order for a mentally retarded person to be considered deinstitutionalized, s/he must have resided in the community (i.e., sleep in and have as a mailing address the community residence), but may have received some day or support services at the institution from which s/he was released.

Community adjustment is defined in this study as an interactive process in which an individual adapts over time to the community environments in which s/he lives (e.g., adaptation to work, school, residence, etc.). The time and budget constraints of this study, however, limited the extent to which this adjustment process could be measured:

- (1) Adjustment could not be measured across two or more time periods--rather, data was collected only at one point in time.
- (2) The study focused almost exclusively on the adaptive behaviors of the individuals to the various contexts and settings in which they live, and did not attempt to examine these settings' adaptation to the demands and needs of the individual.

1.1.3 Organization of Variables

A list of variables related to deinstitutionalization and the community adjustment process was generated by project staff, based on the major research question and theoretical assumptions of the study. Variables were organized into two major sets: (1) dependent variables, or measures of the outcome of community adjustment; and (2) independent variables, or predictors of community adjustment. The sets of independent variables deal with client characteristics and experience prior to release into community settings, and dependent variables describe clients' community experiences and adjustment since release into the community. The relationships among and between these sets of variables are the focus of this study's analysis.

Specifically, three subsets of independent variables are analyzed in terms of their relationships to four subsets of dependent variables.

The independent variables include the following subsets:

- (1) Subject Variables--characteristics of the deinstitutionalized mentally retarded persons (e.g., age, sex, intelligence level, functional level);
- (2) Community Variables--characteristics of the community settings in which clients are placed (e.g., type and size of setting, proximity to shopping and transportation services); and
- (3) Institutional Variables--characteristics of the institution itself (e.g., size, per capita expenditures, staff/client ratios) and of the clients' former institutional experiences (e.g., training received while at institution; work, school, and social activities while at the institution).

The major dependent variables are organized into four subsets:

- (1) Day/Residential Experiences--data related to clients' experiences in day and residential placements in the community (e.g., type of placement(s), client satisfaction with placement(s));
- (2) Services and Training--data on types and frequency of services and training received by clients (and families) since client's release from institution;
- (3) Social and Civic Activities--data on types of activities and frequency of participation by clients since release from the institution (e.g., leisure activities, friendships); and
- (4) Problems and Interpersonal Relationships--data on client and family perceptions of the client's management of interpersonal relationships with day activity participants and staff and community residents in general; and on types of problems encountered by clients and families.

1.1.4 Limitations

A major limitation in developing the conceptual model was the limited amount of previous theoretical and empirical work done in this area. The literature review indicated that little data exists on community adjustment of deinstitutionalized persons, and few, if any, relationships have been established between measures of community adjustment and the deinstitutionalization process. In developing the conceptual model and the specific variables, therefore, there was little to draw upon from previous research. Because a body of knowledge has not yet been established in this area, it is very possible that some important variables may have been overlooked.

The variables selected cover a broad range of issues related to the deinstitutionalization process and community adjustment experiences. Certain types of variables, however, were excluded:

- (1) Variables too difficult to collect, given the cost and scope of the contract. For example, variables potentially related to community adjustment, such as the self-esteem of deinstitutionalized clients or the community acceptance of released clients, are extremely difficult to measure. The time required to develop data in these areas was simply beyond the scope and intent of the study.
- (2) Variables too sensitive to include in interviews: Certain areas of adjustment, such as sexual and legal problems of clients, were considered too sensitive in nature, and potentially offensive to clients, to be included in in-depth interview questionnaires.
- (3) Variables not relevant to the basic focus of the study: The assessment of adjustment through focus on the activities of the clients limited the collection of data in other equally interesting areas. For example, detailed data on the nature of the groups homes to which residents were released, although equally interesting, was not identified as primary for this study.

1.2 Instrument Design

1.2.1 Design of the Institutional Mail Questionnaire (IMQ)

A questionnaire was designed and mailed to approximately 250 institutions identified by the National Center for Health Statistics as serving mentally retarded clients. The instrument was brief, to encourage responses. Its purposes were twofold:

- (1) To provide data on institutions which would enable the project staff to select 10 institutions for participation in the main study of community adjustment of deinstitutionalized mentally retarded persons; and
- (2) To provide data for developing a national "profile" of deinstitutionalization patterns. The profile would be used for two purposes: first, it would stand on its own as a report on these patterns; second, it would provide a base for comparison of the information gathered on the ten institutions used in the deinstitutionalization study.

Data were gathered on the following topics: number of clients served by the facility; number released to various types of community settings;

age and level of retardation of clients placed in various community settings; types of pre-release services and post-release services available; and institutional approval procedures required to contact clients about the study.

Limitations of the IMO

Definitions for some key terms in the Institutional Mail Questionnaire may not have been adequately operationalized. Specifically, no definition was provided for the term "releases." This was an unfortunate oversight. The term "releases" was intended to include both formal discharges and extended visits where the resident lives in the community for an indefinite period of time but is still on the institutional rolls. Undoubtedly, some institutions might have interpreted the term "releases" to mean only formal discharges. To the extent this is true, the numbers reported are biased in favor of more mildly retarded older persons who are more likely to be formally discharged than younger, more severely retarded persons. On the other hand, some institutions might have included short-term visits such as a month's visit to parents, and thus introduced the opposite bias. It is, therefore, difficult to estimate the type of bias resulting from any misunderstandings of this term.

Moreover, no operational definitions were given for types of community placements listed in the questionnaire. An effort was made to choose widely-used terms, but again, their use and meaning varies. Thus, in some states, the term "group home" has a very specific meaning, whereas in others it can include situations in which there are four to fifty residents. This probably did not create too much difficulty, however, as evidenced by the fact that a relatively small proportion of releases were to "other settings" and that a clear definition was provided for "community settings" in general.

1.2.2 Design of the Deinstitutionalization Procedures Questionnaire (DPQ)

The Deinstitutionalization Procedures Questionnaire (DPQ) was developed by project staff to collect information on two major sets of variables: (1) those necessary to produce descriptive case studies on the deinstitutionalization policies and procedures of the 10 facilities; and (2) those necessary to analyze factors contributing to successful community adjustment. A description of the major variables selected for inclusion in this instrument and the rationale for their selection follows:

- Presence of State and Institutional Deinstitutionalization Policies. It was felt that the presence of a formal policy setting forth specific goals related to deinstitutionalization might effect the institutions' placement procedures and the subsequent community adjustment of former residents.
- Presence of State Right to Education Law. A Right to Education Law, if implemented, is likely to improve the range and quality of educational services available to mentally retarded persons both within institutions and within communities. As a result, it might be expected that the presence of such a law would simultaneously improve the preparation and training received by a mentally retarded person while institutionalized, and improve the range and quality of educational services available to that person in the community. Since release from an institution is usually based on a combination of factors including both the readiness of the individual for entering the community and the ability of the community to find reasonable residential and day placements for the individual, it would seem that a strong right to education law would be an important factor to consider when examining deinstitutionalization.
- Presence of Periodic Review Law. Of primary importance for this study was the assumption that, through periodic reviews of institutionalized mentally retarded persons, those people considered to be ready for community placement would be identified; and those who lacked specific community readiness skills would also be identified and provided with the necessary training.
- State Litigation Related to Deinstitutionalization. Class actions and individual litigations concerning mentally retarded persons were investigated for their potential impacts on the institutions' deinstitutionalization policies and procedures. For example, many states' institutions have been involved in right-to-treatment suits in which the quality of institutional programs and facilities have been challenged. The settlement of these court suits has often resulted in additional funds to improve physical conditions, upgrade staffing levels, and increase the number and quality of programs designed to prepare residents for community living.
- Client Assessment Procedures. Institutions vary in the procedures they use to assess and review the needs and progress of residents while living in the institution. The procedures vary in scope (e.g., psychological, educational, social, or vocational assessments), in frequency, and in the types of staff involved. It was assumed that assessments which were comprehensive in scope, frequent, and interdisciplinary might result in more accurate identification of residents' readiness, their needs regarding community living, and more appropriate placements.
- Pre-Release Programs. The types of programs which institutions may develop to prepare clients for placement into community settings include residential and work/school programs both at

the institution and in the community. This study was concerned with the range of different types of pre-release programs and preparation provided residents, as well as the specific characteristics in terms of types of training provided. Since the extent and quality of the pre-release training received by a mentally retarded person prior to release into the community is potentially an important factor affecting eventual adjustment, it was important to obtain detailed information on these programs.

- Release Procedures. The types of procedures and criteria involved in releasing residents from institution to community settings vary greatly, and are likely to influence who gets released to which settings. Therefore, the perceptions of institutional staff regarding the major factors affecting the release process were of interest--e.g., their view of the importance of the functional level of the client, parental attitudes/desires, availability of employment opportunities in the community, and existence of local/county support services.
- Follow-Up Procedures and Support. The nature and source of on-going support and responsibility for care of mentally retarded people living in the community can be expected to affect adjustment. In some states, the institution has primary continuing responsibility for residents after their release to community settings. In these cases, the institution is responsible for maintaining contact with former residents and for providing assistance and services necessary to facilitate their adjustment. In other states, a county or regional welfare or mental health office may assume these responsibilities, or may share them with the institution. This study examined the different arrangements in order to determine their impact on community adjustment.

The majority of the questions in the DPQ were close-ended to facilitate coding and use of the variables in the analysis of community adjustment. Open-ended questions were reserved for variables used only in the case study descriptions. The questionnaire was pre-tested at institutions for the mentally retarded in two states to refine the questions, estimate the time involved in conducting interviews, and to determine appropriate respondents. The questionnaire was then revised on the basis of these pre-tests.

Limitations of the DPQ

A major limitation of the DPQ was that it provided data on deinstitutionalization only from the institutions' perspective. No information was obtained on the views of such significant others as community representatives, consumers, or state officials. In addition, the DPQ dealt only with institutional characteristics presumed to relate directly to deinstitutionalization; thus, no general overview of the characteristics of the institutions can be provided.

1.2.3 Design of the Family Questionnaire (FAMQ)

Variations in the types of settings of clients and their families necessitated the design and use of nine specific questionnaires. In each case, the family of the client was interviewed first.* The client was interviewed separately if able to participate.

Table 1 describes the types of instruments administered and the primary respondents in each setting. As shown in the table, two instruments were used to gather information on deinstitutionalized clients and their families. For example, for clients living in foster homes, two questionnaires were administered--the Foster Parent Questionnaire to the foster parents, and the Resident Questionnaire to the client. By administering two questionnaires in the case of each deinstitutionalized client, the perspective of both the client and his/her "family" were obtained.

Table 2 specifies the types of data collected in each of the nine instruments. As can be seen, the data gathered in all of the questionnaires (except the Resident Questionnaire) were quite similar; they differed only in certain questions specific to the particular setting. For example, in the Natural Parent Questionnaire, certain questions were asked about parent and sibling relationships with the client, whereas in the Housemanager's Questionnaire, questions were asked about the client's relationship with staff and the overall staffing patterns in the group home.

In addition to the questionnaires, the following instruments were also used to gather information about each client:

- (1) Adaptive Behavior Scale (American Association on Mental Deficiency): Administered to the family or contact person about the client's current level of functioning in a variety of domains (e.g., social, vocational, physical, personal). This standardized scale has been used in many related studies in this field. (Referred to as ABS)

* "Families" is used here to refer to the deinstitutionalized client's natural parent or parents; foster parent(s) or guardian(s); group home housemanager(s); or any other person(s) who provide care and supervision to the client in the community setting. In cases where deinstitutionalized persons were living independently, a contact person from the community (such as the client's social worker) was interviewed as well.

Table 1.

Types of Questionnaires and Respondents for
Each Community Setting

Setting in Which Client Lives:	Types of Questionnaires To be Administered:	Types of Respondents:
Clients in Natural/ Adoptive Homes	(NQ) Natural Parent Questionnaire (RQ) Resident Questionnaire	Natural/Adoptive Parents Client
Clients in Foster Homes	(FQ) Foster Parent Quest're (RQ) Resident Questionnaire	Foster Parents Client
Clients in Group Homes	(HQ) Housemanager Quest're (RQ) Resident Questionnaire	Housemanager/House Staff in Group Home Client
Clients in Semi- Independent Settings	(SILQ) Semi-Independent Setting Questionnaire (RQ) Resident Questionnaire	Staff persons working directly w/client in setting (n.g., social workers, rehabilita- tion counselor) Client
Clients in Independent Settings	(ILQ) Independent Living Questionnaire (ILQ-C) ILQ-Contact Questionnaire	Client Person in close con- tact w/client (e.g., social worker, land- lord, employer, etc.)
Clients who have Returned to the Institution	(NQ, FQ, HQ, SILQ, or ILQ-C) * (REQ) Returnee Quest're	Contact person who knew most about client when s/he lived in community Returned client

* In interviewing the returnee contact person, the questionnaire appropriate to the setting in which the client lived while in the community was used. (Questions were phrased in the past tense for the contact person.)

Table 2.

Type of Data to be Collected in
Each Instrument

Instrument	Data to be Collected
(1) Resident Questionnaire:	Client satisfaction with residence; clients' satisfaction with day placement (e.g., work, school, etc.); major problems since leaving institution; skills learned in institution to prepare resident for living in the community; skills which could have been taught at institution to prepare resident for community living; skills acquired by resident since living in the community; skills which resident wants to learn in the community.
(2) Returnee Questionnaire:	Information about when client lived in the community; paralleling Resident Questionnaire data.
(3) Natural Parent Questionnaire:	Background information on resident's relationship to and contact with the client; background information on the client; skills learned in the institution; skills needed by client for living in the community; services used and/or needed by the client and respondent in the community; client's day placement (e.g., school, work, etc.); client's spare time activities; client's socialization in the community; client's community adjustment.
(4) Foster Parent Questionnaire:	(Same as information listed for "Natural Parent Questionnaire")
(5) Housemanager's Questionnaire:	(Same as information listed for "Natural Parent Questionnaire")
(6) Semi-Independent Living Questionnaire:	(Same as information listed for "Natural Parent Questionnaire")
(7) Independent Living Questionnaire:	Background information on client; client's day placement (e.g., school, work, etc.); services used and/or needed by client in the community; client's satisfaction with residence; client's satisfaction with day placement; skills needed to be learned to live in the community; skills learned at the institution.
(8) Questionnaire for Contact Person of Resident in Independent Living Setting:	Background information on respondent's relationship to and contact with the client; respondent's perception of client's community adjustment; skills client learned in the institution; skills client needs to learn to live in the community.

- (2) Final Comments Sheet (FCS): A series of observational scales and impressionistic data filled out by the interviewer after the interview has been completed. The FCS includes data on the interviewer's impressions of the client's adjustment, satisfaction, and social integration; the client's overall appearance (demeanor, cleanliness, dress); the physical condition of the client's home and setting; as well as information on the conduct of the interview itself.
- (3) Client Data Recording Form (CDRF): Demographic information about the client gathered for this study by the institutions from their records. CDRF data included: age, sex, race, level of retardation, number and length of institutionalizations, commitment and discharge status, participation in pre-release programs.

Limitations of the FAMQ

The major limitation encountered in designing these instruments was the fact that little research has been done in this area. Very few studies have attempted systematic data collection with this population group; therefore, few sophisticated scales exist which could be incorporated into the design of these instruments.

In addition, very little is known about the most effective structuring of questions to be used in interviewing mentally retarded clients. The FAMQ relied mostly on closed-ended questions which may have suffered from a narrow perception of what the possible responses were. Open-ended questions were used occasionally in questionnaires administered to clients when the range of possible responses was unknown or unpredictable. These open-ended questions, however, may have erred in the opposite direction of the closed-ended ones; that is, the potential range of responses to these questions ran the risk of being too broad to aggregate and code.

1.3 Study Group Selection

1.3.1 Selection of Respondents for IMQ

A directory was obtained from the National Center on Health Statistics which provided a list of 250 institutions nationally serving mentally retarded persons. The Institutional Mail Questionnaire was mailed to these institutions in the fall of 1974; one hundred fifty-four institutions responded.

1.3.2 Selection of Ten Institutions for DPQ

Of those institutions responding to the Institutional Mail Questionnaire, 26 were identified which met the following four screening criteria:

- (1) The institution must be residential and serve at least 100 clients. Rationale: The cutoff point of a minimum of 100 clients was selected to correspond with the definition of "institution" used in this study (see Glossary).
- (2) The institution must have deinstitutionalized (i.e., released to community settings) at least 50 mentally retarded clients between the ages of 6 and 40 who had been enrolled in the institution for two or more years prior to release, since January 1, 1972. Rationale: In order to arrive at a sample of approximately 500 deinstitutionalized clients, it was imperative that each of the 10 institutions selected had released at least 50 clients. The reasons for including clients within a certain age range and with certain institutional characteristics are given in the section which describes procedures for selecting clients.
- (3) The institution must maintain a list of current addresses or telephone numbers of its deinstitutionalized clients. Rationale: Since the study's procedures for obtaining a sample of deinstitutionalized clients was dependent on the accuracy of the institutions' files on released clients, only institutions which claimed that they had current addresses and telephone numbers of released clients were included.
- (4) The clearance procedures for obtaining consent for the institution to participate and to contact deinstitutionalized clients could not exceed 4 - 6 weeks. Rationale: Each institution indicated through the mail survey the specific clearance procedures necessary for them to participate (e.g., review and approval of institutional officials, state officials, human rights commissions, etc.). Because of the time constraints of this project, only those institutions which anticipated clearance procedures within boundaries reasonable to the project (i.e., less than 4 - 6 weeks) were included in the institutional study group.

Of the pool of 26 institutions meeting the above criteria, 10 were selected using the following guidelines:

- (1) At least 5 states should be represented. It was felt that the 10 institutions should be geographically diverse.
- (2) A wide range of deinstitutionalization processes should be represented, so that the case studies could be as varied and informative as possible.

- (3) States with different types of Right to Education Laws should be represented, since this may be an important potential variable in the deinstitutionalization experience of clients.
- (4) The institution had to be willing to participate. The study was voluntary, and could obviously include only those institutions which consented to participate.

Limitations of the Selection Process on the Data

Three basic limitations are imposed on the data by the process for selecting the ten institutions. First, the initial group of institutions which responded to the mail survey is a self-selected sample. It is impossible to determine whether the institutions which responded differed from non-respondents, since no data on non-respondents was available.

Second, the four screening criteria used to limit the pool of appropriate institutions to 26 further restricted the types of institutions included. They had to be relatively large, have released a fairly large number of clients to community settings, had to have records on the whereabouts of their released clients, and had to have relatively easy clearance procedures. These institutions and the clients released from their programs may well differ from the institutions eliminated during the screening process.

Third, the selection of the final 10 institutions was dependent on the willingness of institutions to participate. Two of the ten initially selected refused to participate, and had to be replaced by other institutions from the pool of 26. One of the institutions refused because of concern about the amount of work involved in participation; another because of recent major administrative staff changes at the institution. It may be that the institutions consenting to participate differed from those which refused. Generalizability of the study findings must be viewed cautiously because of these limitations imposed by the selection procedures. No definitive statements can be made regarding the representativeness of the 10 institutions to the total universe of similar institutions serving mentally retarded clients. However, there is no reason to assume that the ten institutions are unique. A detailed description of the institutions is available in Volume III.

1.3.3 Selection of Deinstitutionalized Clients for FAMO

The sampling pool for selecting deinstitutionalized clients from these ten institutions was based on four basic criteria:

Criterion 1: Clients had to have lived in the institution for two or more years.

Rationale: This requirement was seen as important to control for the confounding effect that relatively brief institutional stays would have on assessing community adjustment.

Criterion 2: Only clients were included who were released from the institution to a community placement.

Rationale: Since the goal of this study was to assess the community adjustment of persons released from institutions, a definition of community was developed. In this study, community placements referred to natural homes, foster homes, group homes, semi-independent and independent living settings (see Glossary for definitions of these specific types of settings). The definition excluded as community placements residential settings which were as large, restrictive, or sheltered as the institution from which the clients were released. Excluded from the definition were placements in state schools and hospitals, nursing homes, residential settings serving over 100 persons.

Criterion 3: Only clients between the ages of 6 and 40 years at the time of release were accepted.

Rationale: The age range of 6 - 40 years was selected in agreement with the Bureau of Education for the Handicapped. While some children under the age of 6 may meet the criterion of two years of institutional experience prior to community placement, the number would have been too small to be analytically useful for this study. Persons over the age of 40 were excluded because many in this age group are deinstitutionalized to nursing or convalescent care settings which did not meet the study's definition of community placement.

Criterion 4: Clients were included only if they were released from the institution between January 1, 1972 and December 31, 1974. Rationale: The time period for releases was arrived at in consultation with the Bureau of Education for the Handicapped. Projections indicated that a 3-year period would be necessary to obtain a sample of 500 released clients. A person was considered "released" if s/he resided in the community (i.e., slept in and had as a mailing address the community residence), and if s/he was explicitly considered to be living either permanently or on a trial basis outside the institution.

Clients meeting all of these criteria constituted the study group pool and are referred to throughout this volume as "target clients." Occasionally, reference is made in the case studies to non-target clients--those released from the institutions who did not meet the criteria specified for inclusion in this study. The distinction made between target and non-target clients is solely a function of this study, and does not indicate a distinction made by institutions or institutional personnel.

Confidentiality and Consent

In order to ensure that the privacy of all deinstitutionalized clients was protected, participating institutions agreed to make initial contacts with clients in the sampling pool. Abt Associates developed a standard letter describing the study, detailing what participation would involve on the part of the client and his/her family, and requesting that they sign and return an enclosed consent form agreeing to participate.

The consent form, developed by a legal consultant experienced in this field, was written in a style which could be understood by a mentally retarded person and/or the client's family. Clients signing the form gave consent to participate in the study, and have basic information about them gathered from the institution (e.g., age, level of retardation, number of years institutionalized, etc.). Legal consent was furnished by the parent or guardian if the client was a minor or judged legally incompetent. If the client was neither a minor nor judged incompetent, the client was required to sign the consent agreement.

The consent forms were sent to the 10 institutions which took responsibility for mailing them to eligible deinstitutionalized clients. Clients and their families were instructed to return the signed consent form directly to Abt Associates if they were interested in participating in the study. In this way, Abt Associates did not make any direct contract with the client and his/her family until after they agreed to participate; and researchers never learned the names of clients who declined participation. Thus, the confidentiality and privacy of both the respondents and non-respondents were ensured.

Response Rate of Sample

One thousand two hundred and forty-two target clients (1,142) were released from the participating institutions. Of these target clients, 919 were living in the community and 323 had subsequently returned to the

institution (i.e., were released and who satisfied our selection criteria during the 1972-1974 period, but who since returned to the institution). Of the 919 non-returnees contacted in the first mailing, only 296 agreed to participate. Therefore, a second mailing was conducted. This procedure yielded an additional 101 non-returnees, thereby increasing the total response from both mailings to 397 non-returnees or 43% of the total 919 non-returnee sample.

It was decided that the study should also interview a sample of the 323 returnees. It was felt that the inclusion of returnees could provide valuable information on a subset of persons who failed to adjust to the community on at least one criterion--remaining in the community. Eight-three (83) returnees agreed to take part or 26% of the total returnee sample.

Ninety-five (95) envelopes never reached the intended clients because of faulty addresses, and in addition, three persons who responded were eliminated from the sampling pool because they did not actually meet the selection criteria (e.g., they were really in nursing homes or they had never in fact been released from the institution). Thus, the total number actually contacted in the first mailing was 1,144 target clients (i.e., 1,242 minus 95).

The total response sample was 480 persons (397 living in the community and 83 returnees) constituting 42% of the 1,144 people actually contacted. It should be noted, however, that the final sample size decreased slightly by unavoidable contingencies in the field, such as clients deciding at the last minute that they did not want to participate, and the presence of conflicting vacation schedules. In sum, the 440 final study members constituted 35% of the 1,242 target group members identified by the institutions.

Limitations of Final Sample Selection Procedures on the Data

Several aspects of the selection process limit the generalizability of the data obtained from the final sample of deinstitutionalized clients. First, the selection criteria and definition of "target" clients were in some ways arbitrary. We could have, for example, used a one-year residence requirement in the institution and/or we could have included a wider (or narrower) age range. There is, of course, no way of knowing the effect of the selection criteria on the composition of the sample and the ensuing results.

Second, the procedure was voluntary. It is impossible to determine whether the persons consenting to participate differed from the non-respondents

since no information was obtained about persons who did not respond or who decided not to participate.

Third, it is possible that the final sample is biased toward persons who did not frequently change residence after release. Letters sent by the institutions to clients requesting their participation never reached 79 clients because their addresses had changed or were incorrect. It is difficult to know whether these persons differed from the final sample of clients.

Finally, the sample may underrepresent clients placed in certain types of settings and overrepresent clients from other types of settings. For example, it is possible that proportionately more clients from group homes and natural homes elected to participate because they were living with or supervised by persons who could assist and encourage them to respond to the request. On the other hand, persons living in independent settings may be underrepresented because there was no one in their immediate setting who could assist or encourage them to respond.

While little can be done about the possible limits introduced by client selection procedures, an attempt will be made in other data presentations to provide descriptions of the clients in great enough detail to permit the reader to pass judgement on the types of clients included in the study.

1.4 Data Gathering

1.4.1 IMQ Data Gathering

The Institutional Mail Questionnaire was mailed in the fall of 1974 to 250 institutions across the country serving mentally retarded persons. A follow-up mailing took place in December, 1974. Virtually all institutions not responding were telephoned during January and February, 1975 to encourage them to respond and to find out why they had not. Through these data collection efforts, 154 institutions responded to the IMQ.

1.4.2 DPQ Data Gathering

Each of the 10 institutions participating in the study were visited by research teams. The objectives of these site visits were threefold:

- (1) To gather data necessary to produce descriptive case studies on the deinstitutionalization procedures and policies of these facilities;

- (2) To gather data on characteristics of the institution identified as possible independent variables in the proposed analysis plan for factors contributing to successful community adjustment; and
- (3) To review with the institutional staff the proposed procedures for contacting the deinstitutionalized clients and for gathering information about them from the institutions' case records.

Four interviewers from Abt Associates experienced in interviewing staff in programs for the mentally retarded visited and administered the DPQ at the 10 sites. The DPQ respondents varied at each site; in most cases, the superintendent of the institution participated, as well as other staff having knowledge of the items covered in the questionnaire. For example, the Director of Social Services or Community Placement, where such positions existed, responded to items in that area. Interviewers were instructed to record the responses of the institutional staff to each questionnaire item in an effort to collect information which could later be reported in a descriptive case study. It generally took six to eight hours to gather the information for the DPQ and to review the proposed procedures for contacting the clients

Limitations of the Data Collection Effort on the Data

There are several limitations imposed by the data collection efforts described above:

- (1) The role of the case studies was primarily descriptive and not evaluative. Moreover, the interviewers merely recorded this information provided by institutional staff, and no effort was made to verify the accuracy of the information due to time and budget constraints. Thus, the reliability and accuracy of the ensuing data might be questioned.
- (2) Although the questionnaire and data requirements of the DPQ were mailed to each institution in advance of the actual site visit, many institutions had difficulty in providing demographic data about the institutions. Often, they felt their records were inaccurate or not updated. In cases where they could not provide exact figures, they were asked to provide their best estimates.
- (3) The DPQ was administered at each site to only a small number of respondents, usually the superintendent of the institution and from one to three other key staff persons. Therefore, the data collected is limited in its perspective. No attempt was made to interview all

of the institutional staff or to obtain a representative view of the deinstitutionalization policies and procedures at the facilities.

- (4) The DPQ was administered in a short period of time-- interviewers generally spent 6 to 8 hours collecting the data for the DPQ. Because of the site visit schedule and the limited descriptive (as opposed to evaluative) role of the case studies, interviewers had little opportunity to observe programs at the institutions or to talk to staff other than the specific DPQ respondents. However, later, in the summer months when the interviews with deinstitutionalized clients took place, many of the field interviewers visited the institutions to observe the pre-release and residential programs in which the clients had participated. In some cases, their observations and information about the institutions were then incorporated into the appropriate case studies.

1.4.3 FAMQ Data Gathering

Field Staff Selection and Training

A total of 14 field staff were hired by Abt Associates to conduct the interviews and gather the data. Two types of field staff were recruited: field interviewers, who were responsible for conducting the interviews with deinstitutionalized clients and their families; and field supervisors, who, in addition to conducting interviews, were also responsible for making the initial contacts with clients and their families; for setting up the entire schedule of interviews for their site; and for supervising the work of field interviewers on their team. The field staff, recruited from universities, school systems, and programs and facilities serving mentally retarded persons, included special education teachers, rehabilitation counselors, group home staff, psychologists, and staff from state institutions for the mentally retarded.

All field staff underwent four days of intensive training. During the initial training sessions, they were introduced to the project and given an orientation to each of the data collection instruments. A training manual outlining all field procedures was provided to each staff member to be utilized on-site. Subsequent training sessions included: an introduction to general interviewing practices; specific instructions for administering each of the instruments to be used in the study; questions and answers about the study which might arise in the field; potential problems in the field and suggested solutions; and item specifications clarifying the intent of each question in each of the instruments.

Role-playing techniques were utilized in the training sessions to give field staff practice in conducting and recording interviews. In addition, a housemanager of a group residence for mentally retarded persons and a mentally retarded client living independently in the community served as sample respondents. Each of the field staff had an opportunity to interview these persons. In order to further orient the staff to the sensitive process of interviewing mentally retarded persons and their families, the Mohawks, a Massachusetts-based group of mentally retarded adults who present training and sensitivity sessions to professionals, met with the field staff to give them feedback on the problems of living in the community and of being interviewed in studies such as the Abt project.

Field Effort

A field staff team was stationed at each of the 10 sites to conduct interviews with clients and their families. In most cases, the team consisted of one field supervisor and one field interviewer. In a few cases, however, the teams were larger because of the number of respondents in that site or because of the distances involved in travelling to respondents' homes. In one case, because of the small number of clients involved, one field supervisor conducted all of the interviews for that area.

The overall field effort was supervised and coordinated by an Abt Associates field coordinator. All field supervisors were required to report to the field coordinator daily while in the field, to discuss the field team's work, problems, and questions.

The interview appointments for field staff were arranged before the actual site visit by the field supervisor of the team. The schedule was arranged to minimize travel time. Thus, a field staff member would conduct the interviews of all clients living in a particular town before travelling on to another area in the site.

Clients were given the choice of being interviewed in their homes, at the institution, at the Abt staff person's hotel, or any other place they requested. Almost all of the interviews were conducted in their homes or at the institution (mostly in the case of returnees). Some clients requested and were interviewed at their place of work so as not to inconvenience their work schedules.

The interviews were conducted during July, August, September, and October of 1975. On the average, field staff members conducted two Family Interviews and two Resident Interviews a day, although this varied depending on the location and type of setting involved. For example, in a group home setting, the field staff member might, in one day, conduct interviews with the housemanager about three clients and then interview each of these three clients individually. This was possible because all of the clients were in one setting and the housemanager served as the respondent for all of these cases. In another case, however, it might have been possible to conduct only one Family and one Resident Interview on a given day if the client was living with his natural family in a rural setting which required 2½ hours of travel time.

Generally, a Family Interview (i.e., using the Natural Parent Questionnaire, the Foster Parent Questionnaire, the Housemanager or Semi-Independent Questionnaire) or an interview with an independently living client (using the Independent Living Questionnaire) took 2 to 3 hours. The interview with the contact person of the independently living client usually took one to 1½ hours; the Resident Questionnaire was completed in about 45 minutes.

After the field effort was completed, a half-day de-briefing meeting was conducted at Abt Associates in order to get feedback from the field staff on their work. At this meeting, overall impressions of the field effort were discussed as well as specific feedback, criticisms, and suggestions regarding particular items on each of the questionnaires.

In general, the field staff felt that they were well received at the sites. The clients, their families, and any staff who participated (at the request of the clients or families) were most cooperative. Although the interview sessions were quite long, the respondents seemed eager to provide field staff with the necessary information. Often, they viewed the interview as an opportunity to vent their feelings and give "their side of the story."

Limitations of Field Procedures on Data

The main limitations of the data imposed by the field procedures used in this study are described below:

- (1) The data was collected during the summer months and early fall. This particular period of time was selected

to meet contract deadlines and to attract competent interviewers who might be more available during this time (e.g., special education teachers, graduate students, etc.). However, certain clients may have been unable to participate in the study because of conflicts in schedule such as vacations. Every attempt was made to schedule appointments at the client's convenience. In fact, in many cases, interviewers returned to certain geographic areas to interview those persons who were excluded in the first wave of interviews because they were unavailable. However, a small number of persons whose schedules could not be accommodated were not included in the study.

- (2) In collecting the data, no attempt was made to verify the accuracy of the information provided by the respondents. The perceptions of the respondents were taken at face value. In cases where two respondents in an interview provided discrepant information, they were contacted to "adjust" the discrepancies. If both parties insisted that their information was accurate, two varying responses were recorded.
- (3) It was difficult to control for the fact that some respondents may have answered questions too positively; that is, they may have overstated how well they were doing in the community in order to please the interviewer or out of fear that information about their adjustment would be fed back to the institution. Every effort was made to reassure respondents about the confidentiality of the information and the importance of responding as honestly as possible. However, there still may have been some respondents who felt compelled, for whatever reason, to respond less than accurately.

1.5 Data Analysis and Reporting

All of the data collected from interviews with institutional staff, clients and their families, and from institutional records are described in this volume. The descriptions present a picture of the institutional and community experiences of 440 clients released from 10 institutions to community settings during 1972-74. It was decided to include these rather lengthy descriptions of the basic variables because of the inherent interest and potential usefulness they have for program planners and service providers. Since the more refined analysis provided in Volume V tends to lose the more qualitative sense of the data, the analysis offered in this volume provides an opportunity to describe the research findings in the most basic and least aggregated form.

The text and tables which were in Volume IV of this report describe the responses of family, clients, and institutional representatives across a variety of topic areas. Ten topic areas are used:

1. Client Characteristics: demographic data on the study group as well as data on their physical characteristics and functional level.
2. Institutional Experiences: descriptions of the clients' experiences when living at the institution before release into the community, including the clients' institutionalization history, types of training/programs received by clients at the institution, and the social experiences of clients at the institution.
3. Community Characteristics as Perceived by Family Respondents: data on the characteristics of the communities in which clients live, including the perceived availability of services and training programs in communities and providers of these services.
4. Residential Experiences: history of the residential experiences of the clients since release from the institution, as well as satisfaction with their current residential settings.
5. Residential Characteristics: descriptions of the types of settings in which clients lived in the community, including physical characteristics, location, size, characteristics of staff/family living with clients, and costs of living in residential setting.
6. Day Activity Experiences: history of previous day activities since release, data on current day activities (work, school, other placements), and client's satisfaction with current day placements.
7. Services and Training: data on types, sources, and frequency of services and training received by clients (and families) since client's release from institution, including institutional follow-up services and case manager assistance.
8. Social and Civic Activities: data on social, civic, and leisure activities of clients in the community, including group activities, friendships, marriages, etc.
9. Problems and Overall Adjustment: client's and family's perceptions of the client's adjustment to family, school, and community; and types of problems of community living encountered by clients and families.
10. Interview Characteristics: information provided by interviewers about the respondents and interview process, including: level of comprehension of the respondents; their attitude toward the interview; the demeanor and verbalness of the client, and the length of time taken to complete the interview.

Limitations of Data Reporting

The major limitation in describing this data is that it is merely a description--it does not attempt to interpret or explain the types and frequencies of experiences which are reported. It is anticipated that interpretations and/or explanations of the data will occur in Volume V after a variety of analytical techniques have been applied.

1.6 Steps Used in the Analysis

The major task confronting the analysis of the deinstitutionalization data was the reduction of the approximately 2500 variables to a number small enough to make the analysis feasible, while ensuring that the final variables used in the analysis still retained conceptual and practical meaning. That is, while it was necessary to reduce the number of variables, wherever possible when composite variables that were created were related directly to the characteristics observed in the field, rather than "underlying" factors that would be difficult to measure or conceptualize. Indeed, throughout the conduct of the analysis an emphasis was maintained on the conceptual framework that has provided the basis for the conduct of the study and for the selection of variables. Thus, as the steps described below were taken to reduce the number of variables and carry out the final analyses, the following main categories of variables were retained.

1. Individual Characteristics: These were divided throughout into two main categories:
 - (a) Demographic/descriptive information including age, sex, level of retardation, disabilities,
 - (b) Institutional experiences including length of time institutionalized;
2. Institutional Characteristics: including size, type of programming provided, policies with respect to community support;
3. Community Characteristics: including amount of services provided, primary providers of community services;
4. Community Experience Variables: These were divided into:
 - (a) Residential experiences including type of setting, number of moves,
 - (b) Day placement experiences including types of placement, number of placements, hours spent in day activities,
 - (c) Social experiences including friends, leisure time activities,
 - (d) Problems and adjustment,
 - (e) Services and training including number of services received, type of service received, frequency of use, and unmet need for service,
 - (f) Returning to the institution vs. staying in the community.

Step 1: Eliminated Variables

Many of the 2500 variables were eliminated from possible inclusion in the analysis for the following reasons:

1. There were many variables that were not obtained on every member of the study group, but which were only gathered for those living in certain settings. For example, information was obtained on the staffing patterns in group homes and semi-independent living situations but not on foster or natural homes or independent living situations. A set of "core variables" was thus established consisted of those variables asked of all members of the study group. This group contained approximately 1500 core variables.

2. There were, within the core variables, a number of variables that missing cases for reasons other than that they were unique to a particular setting. The reasons for a large number of missing cases included difficulty in understanding an item (particularly for questions asked of the resident), skip logics, or modifications in the questionnaire that occurred between the first and second wave of interviews. If 25 percent or more of the cases were missing for a variable, it was eliminated.

3. There were a substantial number of variables that had virtually no variation in the responses given. While this small amount of variation was interesting descriptively, it rendered the variable unusable for the analysis. If more than 90 percent of the study group gave any one response to an item, the variable was eliminated.

4. There were some items that simply did not work very well, and it was recognized that the information obtained was not very accurate. These were therefore eliminated from the analysis. These variables included information on income sources (this item was confused because of the many channels that money goes through to provide support either directly to the mentally retarded person or to his/her family); and the questions on the "adequacy" of services and training which interviewers felt was not answered accurately by respondents.

After all the above steps were taken to eliminate variables, well under 1000 variables remained.

Step 2: Condensed Variables

The next step taken was to condense as many of the variables as possible into a variety of scales and composite variables. As was indicated above, whenever possible this was done conceptually and was done to retain the meaning and measurability of the new variable. Thus, factor analysis or other purely statistical techniques were not used very often.

1. A large number of linear unweighted scales were created through simple counts of certain groups of variables. For example, counts were made of the number of services and training received by the clients. In these counts it was assumed that each type of service and training was of equal importance. Although this assumption could well be challenged, it was decided that the equal weighting assumption was the simplest one to make particularly without a strong conceptual basis for arguing that one type of training or one type of service would, for all mentally retarded individuals, be of substantially more importance than another -- and that this importance would be the same for all clients.

2. There were, however, some items that were weighted by their importance, if that importance had been provided by the respondent. For example, residents' problems were assigned weightings that gave a problem a value of 1 if it was not a problem for an individual, a value of 2 if it was "somewhat" of a problem, and a value of 3 if it was reported to be a "big" problem. Here again, all "big" problems were considered to be equally important, etc. As with equal weightings, there could be disagreements with the particular values assigned, but the weightings were consistent within the study group.

3. Some scales were created by weighting the variables by their frequency of occurrence. For example, spare time activities were weighted with a 0 if the resident did not participate in the activity at all, a 1 for participation once a year or less, a 2 for at least twice a year, a 3 for at least once a month, and a 4 for at least once a week. An activity in which a resident participated once a week was given a weighting four times as much as one in which s/he participated only once a year. Thus, the higher the score, the higher the level of participation.

4. Some scales were created by weighting the variables by their importance as reported by respondents in terms of need. Specifically, this was used for services and training. For these variables a type of service or training which was not used because it was not needed was given a score of 1, services or training used (and assumed to have been needed) were given a score of 2, and those services not used but needed, a value of 3. Thus, the higher the total score, the higher the unmet need.

5. Some scales were created by measuring changes over time. Thus, for both day and residential history scores were given to individuals based upon the number of moves and the average length of stay in each placement.

6. A few scales were created through factor analysis. For example, a composite variable measuring both total length of time institutionalized and the average length of time institutionalized for each stay in the institution was created. Other variables were created later in the analysis by performing factor analyses and correlations on small groups of variables that had been clustered conceptually. The correlations and factor analyses indicated which variables tended to be highly related to each other. At this point, the variables were either added together in an unweighted scale or were first standardized and then added together.

It should be noted that the following procedures were used to deal with missing values when scales were being created.

1. When a scale was being created by adding a series of variables, either unweighted or weighted, a cut-off of 75 percent was used: If an individual case had at least 75 percent of the variables being included in the scale, then the case was assigned its own average score for the variables that were present to those variables for which scores were missing. That is, the individual mean score was used. If a case was missing more than 75 percent of the variables, then the case was eliminated, and did not get a value on the new variable.

2. For variables missing up to 25 percent of the cases, the group mean was assigned to those cases. This was particularly important when computing factor analyses, since the only cases that would have remained would have been those not missing any of the variables included in the factor analysis. This would have reduced the size of the sample substantially, making the factor analysis unusable.

Step 3: Correlations

There were by now slightly over 100 variables, some of which were composites (as described above) and some of which were unitary variables (e.g., age, sex, IQ). The total group of variables was divided into two conceptual sets: (1) independent or predictor variables; and (2) dependent or outcome variables. This distinction was not always straightforward. For some it was relatively easy to determine where they belonged. These were the individual, institutional, and community variables -- all of which were considered "independent" or "predictor" variables. It was considerably more difficult with some of the community experience variables. For example, is unmet need an independent variable that is likely to predict "adjustment," or is it a measure of adjustment? Ultimately, a decision was made to treat these variables both as dependent variables, reflecting the quality of an individual's community experience, and as independent variables, predicting the likelihood of remaining in the community.

Correlations were run to determine the following:

1. Which variables should not be included in a regression because they were not correlated with any other variables and would therefore not show up in a regression equation.
2. Which variables were so highly correlated that they should be combined into new variables.

Step 4: Final Reduction of Variables

Based upon the correlations and the conceptual framework, additional composite variables were finally created. A few unitary variables such as sex were kept in the final analysis because of their conceptual importance despite the fact that they had not shown high correlations with other important variables.

The final list of variables used in the analysis is described in detail in Section 3 below. An abbreviated version follows.

Table 3:

FINAL LIST OF VARIABLES SUBJECTED TO ANALYSIS

<u>OUTCOME VARIABLES</u>	<u>COMPONENTS, IF ANY</u>
1. Returning to institution/staying in community	
2. Total activity level	a. total day activities b. total spare time activities
3. Problems	a. problems for the mentally retarded person b. problems for the family of the mentally retarded person
4. Restrictiveness of residential setting	a. type of residential setting b. freedoms permitted in residential setting
5. Unmet need	a. unmet need for services b. unmet need for training
<u>PREDICTOR VARIABLES</u>	
A. <u>Individual Characteristics</u>	
1. Age	
2. Sex	
3. Level of retardation	
4. Score on Part I, ABS: functional level	
5. Score on Part II, ABS: undesirable behaviors	
B. <u>Institutional Experiences</u>	
1. Age at first admission	
2. Length of institutionalization	a. total length of time institutionalized b. average length of time institutionalized for each stay
3. Institutional training	
4. Institutional spare time activities	
C. <u>Institutional Characteristics</u>	
1. Length of time a periodic review policy has been in effect	
2. Degree of institutional support to community	a. institutional training of families and residential staff b. institutional training of day program staff c. continued responsibility by institution in community
3. Intensity of institutional programming	a. per capita expenditures b. amount of institutional pre-release training
4. Family satisfaction with pre-release preparation	
D. <u>Community Characteristics</u>	
1. Amount of services and training provided	a. count of services for residents provided and available b. count of training for residents provided and available, if needed c. count of support services for families provided and available, if needed d. amount of staffing
2. Amount of services available in community	a. count of services perceived as available by institution b. count of residential alternatives
3. Amount of support provided by institution in community	a. amount of follow-up b. percentage of all services and training for residents and support services for families provided by institution

Step 5: Analysis of Variance

The next step in the analysis was two sets of analyses of variance: one that looked at the differences between children (age 18 and under) and adults (over age 18) in the study group on each of the final 22 variables (not including age); a second that compared mildly, moderately, and severe/profoundly retarded study group members on the remaining 22 variables. The Tukey ANOVA technique was used, with a .05 level of significance being used to indicate significant differences among the groups. However, other variables were described if they were close to significant, or if the fact that no differences appeared was considered interesting.

Step 6: Final Correlations

Correlations were calculated for the final list of 22 variables. This correlation matrix was examined to pick out both interesting high correlations, and any correlations that were surprisingly low. A cut-off of approximately .25 was used to consider a correlation to be "high." The relatively large sample size meant that correlations as low as .09 would be significant at the .05 level; thus, level of significance was not used as the criterion for inclusion.

Step 7: Regressions

The final step in the analysis was a set of step-wise regressions. Regressions were performed that used staying in the community/returning to the institution as the single dependent variable, using the remaining 22 variables as predictors. Additional regressions were performed using as the outcome variables each of the community experience variables, and using the remaining 17 variables as predictors. The variables included in the regression equation reported were those whose F value was significant at approximately the .05 level. The variables are reported in the order in which they went into the equation, and the significance of their F is reported. In addition, the significances of the overall regression equation is reported, along with the variance (R^2) accounted for by the equation.

2.0 DISTRIBUTION OF THE FINAL VARIABLES

In this section each of the final variables that is used in the analysis is described in terms of its distribution in the total study group. Because many of the final variables were composites, some of which would be difficult to interpret if their distributions were reported, some of the component variables are described rather than the composites themselves.

2.1 Outcome Variables

1. Returning to the institution vs. staying in the community: Out of the total 440 study group members 53 (12%) were "returnees" and the remaining 357 (88%) were "non-returnees." Major descriptive differences between these groups are reported in detail in Volume IV of this project.

2. Total activity level: This is a composite variable including both spare time activities and day program activities.

a. Day Programs: Individual members of the study group could be more than one activity labeled in the study as a "day" program. These included work placements (sheltered or competitive), school placements (day or night), and day activity programs. The following table shows the number of day placements in which the study group members were participating at the time of the interview or, for returnees, just prior to their return to the institution:

<u>Number of day Concurrent Placements</u>	<u>Absolute Frequency</u>	<u>Relative Frequency (percent)</u>	<u>Adjusted Frequency (percent)</u>	<u>Cumulative Frequency (percent)</u>
none	50	11.4	11.4	11.4
1	249	56.6	56.6	68.0
2	137	31.1	31.1	99.1
3	4	.9	.9	100.0
	440	100.0	100.0	

The mean number of day placements for study group members was 1.216, the median was 1.185.

There were, altogether, a total of 485 different placements in which the 440 study group members were participating. Of these, 235 or 48% were either sheltered or competitive job placements (59 were competitive, 186 were sheltered); 188 (39%) were school placements (58 were night school programs, 130 were day programs); and the remaining 120 (25%) were day activity center programs. Thus, school and sheltered work situations were the most common placements for the study group, with a total of 50 individuals not in any placement at all.

A count was made of the total number of hours spent by the study group members each week in their day activities. The total number of hours ranged from 0 to 80 hours a week, with a mean of 29.4 hours a week, and a median of 31.6 hours a week.

b. Spare Time Activities: There were thirteen different spare time activities in which the study group members could participate. Each activity was weighted into a total score by the frequency with which the individual participated, from 0 for no participation to 4 for weekly participation. Thus, the total possible score for an individual was 52 (13 times 4). The actual scores ranged between 0 and 52, with a mean score of 26.7 and a median score of 28. This can be interpreted to mean that if study group members were participating in all thirteen activities, they were doing so on about a monthly basis for each of the activities. The activities in which study group members were most likely to participate and in which they participated most frequently was, not surprisingly, watching TV or listening to the radio. Other popular spare time activities (both in terms of how many study group members participated and the frequency of their participation) were running errands, hobbies, and playing sports. Among the least popular activities were attending association or club meetings and going on dates.

3. Problems: Two sets of questions were asked about problems: problems that the mentally retarded person him/herself was having in the community (e.g., finding or keeping a job), and problems that the family had in dealing with the mentally retarded person (e.g., lack of client self-care skills). For each problem listed, the family respondents were asked if it were a "big problem" (scored 3), "somewhat of a problem" (scored 2), or "not a problem" (scored 1). A score was created combining the two items and weighting each problem by a 1, 2 or 3

The most common problems that families perceived that the residents were having were finding or keeping a job, and family relationships. These problems were most likely to be perceived as "big" problems, and were least likely to be perceived as "not a problem." The biggest problems for the families in dealing with the mentally retarded individual were discipline problems and (resultant) stress on family relations. The smallest problems for residents were perceived to be staying out of trouble with the law, socially unacceptable behavior, and finding needed services. For families, the least important problem of those listed included meeting the resident's medical and financial needs.

For the set of problems dealing with the resident, the average problems were perceived by family respondents to be "somewhat" of a problem (on a three point scale ranging from 1 for not a problem to 3 for a big problem, the mean score across all problems was 1.43). For the family's problems the score was slightly lower, but would still constitute "somewhat" of a problem on the average. (The mean score was 1.379 for this group of problems.) The range for the residents' problems was from 1 (with 41 study group members reporting not having any problems) to a high of 2.5 for 2 study group members. That is, for no study group members were all thirteen problems "big" ones. Approximately one-third of the study group had a mean score of 1.25 or less, thus indicating that on the average 75 percent of the problems listed were not problems at all. Only about 10 percent of the total study group had a mean score of 2.00 or higher, indicating that most of the problems listed were "important," for relatively few of the total study groups.

For the families' problems, the range was from 1.00 (53 cases) to a high of 2.67 (1 case). As with the residents' problems, the distribution was skewed towards few problems, with almost half of the study group having a score of 1.25 or less. Less than 6 percent of the study group had a score of 2.00 or higher. In general, then, it seems that most of the study group had some problems or presented some problems to their families, but for relatively few were there large numbers of "big" problems.

4. Restrictiveness of Residential Setting: Highly related to the problems is the restrictiveness of the settings in which study group members lived. This concept was developed from two measures: the type of setting,

and the activities that the resident was allowed to do in the setting. At the time of the interview (and just prior to return to the institution for returnees) the study group was living in the following settings:

Natural/adoptive homes	61 (13.9%)
Foster homes	78 (17.7%)
Group homes	209 (47.5%)
Semi-independent living settings	44 (10.0%)
Independent living situations	48 (10.9%)

Each setting was assigned a score, based upon a judgment of its restrictiveness. In the order listed above, natural/adoptive homes were judged to be the most restrictive, independent living situations the least restrictive. Arguments could be made, particularly with respect to the differences between natural/adoptive homes and foster homes on this dimension. Also, there could well be group homes that are more restrictive than some foster or natural homes. Despite these possible disagreements, the overall direction of "independence/restrictiveness" seems to be clear.

The second aspect of restrictiveness that was measured was a count of the number of pre-listed activities that the residence allowed the study group member to decide for him/herself. These included having a guest for dinner, deciding one's own bedtime, shopping for clothing, and drinking alcoholic beverages. On this dimension, there were eleven different activities that the resident could be allowed to do in the residence. There were 18 individuals who were not allowed to do any of the activities and 90 who were allowed to do all the activities. The mean number of activities allowed was 7.286 and median was 7.962.

5. Unmet Need: This was a count of the total number of training and services that could be used by a mentally retarded person in the community. The count was weighted: a type of service or training that was not used because it was not needed, was assigned a value of 1; an item was used (and presumed to be needed), was assigned a value of 2; and a 3 was assigned to items that were not used, but were needed. Thus, the higher the score, the higher the amount of "unmet need." There was a total of 35 different types of services and training listed. The possible range in

scores was therefore 35 to 105. The actual range of responses was from 60 (1 case) to 104 (1 case). The mean score for the total study group was 84.027, with a median of 83.003. For 35 different services and training, this is an average score of about 2.4, somewhere between "needed and used" and "needed and not used." Virtually none of the study group members had an average score of 2.00 or less (under 2 percent, indicating that on the average few study group members were not receiving services and training because they did not need them. At the other extreme, almost 30 percent of the study group had an average score of 2.5 or higher, indicating that for them, most of their needs were not being met.

2.2 Predictor Variables

2.2.1 Individual Characteristics

1. Age: This variable measured the age of the study group members at the time of the interview. Although the original criteria for inclusion in the study group had age limits of from 6 to 40 at time of release from the institution, the institutions had mistakenly included some individuals who were either above or below these age cut-offs. To retain the sample size, and because exact age was not learned until the interview itself, individuals outside the prescribed age were retained in the final study group. The actual age range of the study group was from 5 to 66 years old. The mean age was 26.6, the median was 25.3 years old. Of the total study group 83 (18.9 percent) were "children" aged 18 and under, and the remaining 357 (81.1 percent) were "adults." Within the adult group, 36 (8.1 percent) of the total study group were over age 40.

2. Sex: The study group was almost evenly divided between males and females: 235 (53.4 percent) were males, and 205 (46.6 percent) were females.

3. Level of Retardation: The study group was divided into four groups by level of retardation: mild, moderate, severe, and profound. The definition used was taken from the AAMD Manual on Terminology and Classification in Mental Retardation, (Special Publications Series No. 2, 1975).

Level of Retardation

Mild (IQ 68-52)	177	(41.4%)
Moderate (IQ 51-36)	141	(33.0%)
Severe (IQ 35-20)	88	(20.5%)
Profound (IQ 19 and below)	18	(4.2%)
Unknown	3	(1.0%)

4. Score on Part I, ABS: Functional Level: This was the raw score obtained by the individual study group members to Part I of the Adaptive Behavior Scale developed by the AAMD. It is difficult to interpret these raw scores without using an age baseline to determine the extent to which an individual is functioning below expected developmental level. However, the raw score can be taken as a measure of absolute performance in terms of functional capacity and was therefore used as is. A maximum score of 280 was possible on the Part I of the ABS, indicating maximum functional level measured. The study group scores ranged from 19 (1 case) to 272 (1 case). The mean score for the group was 207.164, and the median was 220. About one-third of the total study group had a score under 200 on the total Part I of the ABS.

5. Score on Part II, ABS: Undesirable Behaviors: Part II of the Adaptive Behavior Scale measured the number and frequency of undesirable behaviors. For each of 288 different behaviors an individual would receive a score of zero if the behavior was not present, a one if it occurred occasionally, and a two if it occurred frequently. Thus, the higher the score the more undesirable behaviors. The total range, then, was from 0 to 576. For the study group the actual range was from 0 (14 cases) to 226 (1 case). The mean score was 31.537, and the median score was 20.214. Only 20 percent of the study group had a score over 50, and only about 5 percent had a score of 100 or more. Thus, for the vast majority of the study group, relatively few negative behaviors were present.

2.2.2 Institutional Experiences

1. Age at First Admission: The age at which the study group member was first admitted to the releasing institution was obtained from institutional records. The age at first admission ranged from one year to 57.4 years.

The mean age of first admission was 13.3 years, and the median age was 12 years. Sixty-five individuals (15.6 percent) were first institutionalized at age six or younger.

2. Length of Institutionalization: This is a factor that combines the total length of time a resident was institutionalized with the average length of time spent during each period of institutionalization.

a. Total time institutionalized: It should be recalled that a criterion for inclusion in the study group was that the individual had been institutionalized for at least two years prior to release. In general this was the case. However, the actual total time institutionalized range from 12 months (2 cases) to 702 months (58.5 years) (1 case). The mean length of time institutionalized was 245 months (20.4 years), and the median was 240 months (12 years). Only five study group members had been institutionalized less than two years total. Less than one-quarter (22.5 percent) had been institutionalized ten years or less. Slightly over twenty percent had been institutionalized more than thirty years, and seventeen individuals had been institutionalized for forty years or more.

b. Average length of each institutional stay: Many of the study group had been institutionalized more than once. The average length of time spent institutionalized during each stay ranged from one to forty years, with a mean of 10.9 years and a median of 8.3 years.

3. Institutional Training: This variable measured the total number of different day programs in which the mentally retarded person had participated at the institution prior to release. The range for the study group was 0 (125 cases), 1 (228 cases), and 2 or more programs (87 cases). The mean number of day programs in which they participated was .914, and the median was .917.

4. Institutional Spare Time Activities: This variable measured the number and frequency of the same list of spare time activities used for community experiences. As with community activities, the most common spare time activities both in terms of number of study group members who participated at all and the frequency with which they participated, was watching television

or listening to the radio, with going to movies and parties also very common. Those activities that were least common were dating, visiting friends, having hobbies, and attending clubs. Overall, if study group members participated in all thirteen activities, they did so on an average of once a month.

2.2.3 Institutional Characteristics

There were nine institutions from which study group members had been released. Most of the information gathered about the institution was gathered from institutional staff. Additional information was obtained, however, through the family interviews. Most of the variables described below were based upon information gathered at the institution, one was from the family. The study group distributed itself as follows from the 9 institutions, listed in order of the number of study group members:

Institution #1:	103 (23.4%)
Institution #2:	55 (12.5%)
Institution #3:	55 (12.5%)
Institution #4:	46 (10.5%)
Institution #5:	46 (10.5%)
Institution #6:	38 (8.6%)
Institution #7:	37 (8.4%)
Institution #8:	36 (8.2%)
Institution #9:	24 (5.5%)

1. Length of Time a Periodic Review Policy had been in Effect: This variable measured, in months, the length of time that a periodic review policy (at the state or institutional level) had been in effect as of July 1975. This ranged from only five months for one of the institutions (in which there were 55 study group members) to 97 months for one of the institutions (in which there were 37 study group members). The average length of time that the policy had been in effect for the eight institutions that had the information was 40.63 months. Study group members were assigned the score obtained by their releasing institution. The mean for study group members was 36.3 months, the median was 29.718 months. Thus, most of the study group members were in institutions which had had a periodic review policy in effect for between two and three years as of July 1975. This

means that for many of the study group members, the policy was just being implemented at the time of their release (between January 1972 and December 1974).

2. Degree of Institutional Support to Community: This variable was a count of the number of policies the institution had regarding support in the community for deinstitutionalized clients. Specifically, these policies and the number of study group members coming from institutions with each policy were:

<u>Institution Policy</u>	<u>Yes</u>	<u>No</u>
Does the institution retain <u>any</u> continuing responsibility for the individual's well-being after s/he has been placed?	301 (68.4%)	139 (31.6%)
In 1972, 1973, and/or 1974 did the institution provide any training to study group <u>families</u> to prepare them to work with the clients?	207 (47.0%)	233 (53.0%)
In 1972, 1973, and/or 1974 did the institution provide any training to <u>teachers and/or employers</u> of the study group to facilitate placement and ensure its long-term success?	262 (59.5%)	178 (40.5%)

The scores could range, with a value of 1 for each "yes" and 2 for each "no" from 3 to 6. The distribution was 171 study group members or 38.9 percent were from institutions having all three policies, and 103 or 23.4 percent from institutions not having any of the policies.

3. Intensity of Institutional Programming: This was a composite variable that included the average per capita annual expenditure for the institution (for the year 1973), and the average percentage of the clients released by the institution that participated in a variety of institutional programs.

a. Institutional Programs: There were four different types of programs that the institutions could provide for pre-release preparation of residents: competitive job opportunities, sheltered job opportunities, school programs, and day activities programs. Institutions were asked to indicate what percentage of their released clients participated in each type of program. These responses were then assigned to the individual members of the study group.

The least common type of program was competitive work situations. Seven of the nine institutions had such programs, with a range of from 3 percent to 32 percent of their released clients participating. The average member of the study group came from an institution providing competitive work opportunities to 12 percent of the clients it released to the community. Eight of the institutions provided some type of sheltered work programs for clients released to the community, with a range of from 3 percent to 63 percent of their clients participating. The average member of the study group was released from an institution providing sheltered job opportunities to 34.7 percent of its released clients. Seven institutions provided a special school program to prepare clients for release to the community, with a range of from 2 percent to 28 percent of the clients released receiving this schooling. The average member of the study group was released from an institution which provided schooling to only 6.2 percent of its population as part of its pre-release preparation. This may be accounted for largely by the fact that most of the people released are adults, and by the fact that for many of the adults released, some type of schooling had been provided not as part of pre-release preparation but as part of their normal institutional programming. Six institutions provided day activity programming for clients prior to their release into the community, with a range of from 3 percent to 80 percent of the released clients participating. The average study group member was released from an institution providing day activity programs to 17.7 percent of its released clients.

b. Per Capita Expenditures: The annual per capita expenditures for the releasing institutions during 1973 was obtained from eight of the institutions. The annual per capita expenditures ranged between \$6477 and \$10,429. The average member of the study group was released from an institution spending \$7940 per capita annually.

c. Family Satisfaction with Pre-Release Programming: This was a three-point scale measuring families' expressed satisfaction with the various types of preparation that the mentally retarded individual had received prior to release into the community. Of the family respondents, 182 (41.4 percent) were satisfied with the pre-release preparation received by study group members, 74 (16.8 percent) were neither satisfied nor dissatisfied, and 125 (28.4 percent) were dissatisfied (and another 59 or 13.4 percent did not respond). Thus, while on the average respondents tended to be reasonably satisfied with pre-release preparation, a fairly large group were not.

2.2.4 Community Characteristics

1. Amount of Services and Training Provided: This is a composite measure including both amount of services provided and amount of staffing and staff support for families.

a. Count of Services Provided in the Community to Clients: This is a count of the total number of different services and providers of services available to mentally retarded residents and their families. Included was a count of all types of training, services and family support services. Included in the count was any service or training that was used by a client or a family, plus any services that respondents indicated were needed and available. Excluded, then, was any indication of whether services that were not needed would have been available had the need arisen. The count is therefore biased towards a higher count for persons needing services than for those not needing services. It can be assumed, however, that the availability of services and training for those needing them less would be of less importance. It should also be noted that the provider of these services could be the residence, a community agency or provider, or the institution -- as long as it was available to users living in the community it was included in the count.

There were a total of 44 possible types of services and training that could be provided for the resident and his/her family in the community. The actual range for the study group was from no services or training (1 case) to 36 types of services and training (3 cases). The mean number of services and training provided was 20.307, the median was 21.935. That is, for approximately half the study group, approximately half the total range of possible services and training were either actually used or potentially available.

b. Amount of Staffing: This was a factor that included both the average years of education of the staff of a residence (including parents in a natural or foster home), and the extent to which they used support services.

(1) Average Years of Education of Residence Staff: The average number of years of education of family members ranged from 2.5 years (1 case) to 21 years (4 cases). The mean number of years of education which staff

had was 13.283, and the median was 13.727 years. That is, for most of the study group members, the average adult who was responsible for their supervision had about two years of college.

(2) Use of Support Services: Family members could use up to 6 different types of support services. The actual range was from 0 (91 cases) to 5 types of service (24 cases). The mean number of services used by family members was 2.284 and the median number of services used was 2.559.

2. Amount of Services Available: This is a composite variable that is basically a count of the number of services reported as being available in the community, not necessarily actually used.

a. Count of Services Reported by Institutions as being Available: Institutions were asked to indicate whether or not each of eight services were available in the community to released clients. The actual range report was from 0 to 8. Each individual in the study group was assigned a score reported by the community. The mean number of services reported was 3.982, and the median was 4.013. Thus, the average study group member was being released from an institution that perceived that about half the listed services would be available to the client.

b. Count of Alternative Residential Settings: Families were asked whether or not residential settings would be available in the community to the mentally retarded person that would provide either less or more supervision than did the current setting. Over 40 percent of the study group lived in communities in which there were no alternatives. Another 40 percent lived in communities where there were either more supervised or less supervised settings available, but not both; the remainder lived in communities having both more and less supervised alternatives available.

3. Amount of Support Provided by Institution in Community: This variable combined the amount of follow-up provided by the institution to residents in the community, and the percentage of all services provided and potentially available to mentally retarded persons and their families that were provided by the institution rather than by the community.

a. Amount of Follow-Up Provided to Clients in the Community

by the Institution: This variable was based upon the families' responses about the amount of follow-up that they perceived the client as having received since release into the community. It was weighted by the frequency of the contact by institutional staff: a 0 was no contact, 1 was less than once a year, 2 at least once a year, 3 at least twice a year, 4 at least monthly, and 5 at least once a week. The actual range reported was from 0 (178 cases) to 5 (60 cases). The mean frequency reported was 2.098, the median was 1.938. Thus, the average member of the study group was receiving follow-up from the releasing institution at least twice a year, while about 40 percent were not followed-up at all (as far as the family respondent knew).

b. Percentage of all Services and Training Provided by the

Institution: A count was made of all the different services and training for mentally retarded persons, and the support services for families that were reported by respondents as either having been used or as being potentially available if needed. (This is the same count reported above as amount of training and services available in the community.) The source of each type of service or training was identified, and based upon this the percentage of times that the institution was cited as the source was calculated. For most of the study group (244 cases or 55.5 percent) none of the services provided mentally retarded persons and their families were available through the institution, and for one case all services and training were available through the institution rather than through communities sources. The mean percentage of support provided by the institution was 9.025, and the median was .402 percent. Only 2.5 percent of the study group lived in communities in which half or more of the services and training available to them was provided by the institution.

3.0 ANALYSIS OF VARIANCE (ANOVA) RESULTS

An analysis of variance was performed to determine whether or not there were any interesting differences within the study group according to the level of retardation and the age of the clients. Study group members were classified according to three levels of retardation: (1) mild; (2) moderate; and (3) severe and profound. They were grouped into two age categories: (1) children (aged 18 and under); and (2) adults (aged 19 and over). There were 83 children and 357 adults in the study group. Information on level of retardation was only available on 414 of the 440 study group members. Of these, 171 were mildly retarded, 137 were moderately retarded, and 106 were severely or profoundly retarded.

One way ANOVAs using Tukey's technique, and a cut-off of .05 for "significant" differences among the groups were performed. In this section the important differences, and some of the interesting instances in which there were no differences among the groups, are described.

3.1 Differences According to Client Age

1. Differences in Individual Characteristics: Not surprisingly, since functional level is known to be associated directly with age, a significant difference was found in the study group between the children and the adults on Part I of the Adaptive Behavior Scale. The children scored significantly ($p < .001$) lower than did the adults. Equally interesting is that no significant difference was found between children and adults on Part II of the Adaptive Behavior Scales (negative behaviors). There was, however, a slight tendency for children to have fewer behavior problems than did adults, as measured by the ABS scores.

Related to the difference in functional level between the children and the adults was the significant difference between the two groups in level of retardation: the children were significantly more retarded than were adults, as measured by the four levels of retardation: mild, moderate, severe, and profound. While both children and adults were generally moderately retarded in the study group, adults on the average were between moderately and mildly retarded, while the children were between moderately and severely retarded. This tendency is perhaps related to the history of institutionalization and deinstitutionalization in this country: the first people who have

been released have been the mildly retarded adults who are unlikely to ever be institutionalized at all, and hence those that are released are likely to be more retarded. Also, more severely retarded adults are perhaps likely to be perceived as more difficult to place in the community than severely retarded children.

No significant difference was found between children and adults in the study group in terms of the proportion of males and females: both were about half male, half female.

2. Differences in Terms of Institutional Experiences: Not surprisingly, children and adults had quite different histories of institutionalization. Out of four variables examined, children and adults differed significantly on all four of them. Children had spent significantly less time in the institution than had adults, and were admitted at a significantly younger age than adults, ($p < .001$ in both instances). The children in the study group had been admitted to the institution, on the average, at the age of about 10 years old, whereas adults in the study group had been admitted for the first time when they were 14 years old.

Children had had significantly fewer spare time activities while institutionalized than did adults ($p < .001$). Children had participated in significantly fewer day programs (mean = .5663) than had adults (mean = .9944) while institutionalized.

3. Differences in Terms of Characteristics of Releasing Institutions: There were no differences between children and adults in terms of the length of time a periodic review policy had been in effect, family satisfaction with pre-release preparation of children versus adults, or the overall intensity of programming and expenditures of the releasing institution. However, there was a significant difference ($p = .006$) between children and adults in terms of the extent to which the releasing institution felt a continued responsibility for the clients after placement in the community: children tended to be released from institutions that were more likely to have a continued responsibility than were adults. This raises some interesting questions in terms of the direction of this relationship: is it that institutions feel more continued responsibility towards children than they do towards adults that for this reason institutions releasing more children tend to be more involved with the community,

or is it that those institutions that have more contact with the community are, as a result of this contact, more likely to release children? This question cannot be answered through this study, but is an interesting one to raise, particularly considering the importance of this variable in predicting returning to the institution (see Section 5.0 below).

4. Differences in Community Characteristics: An interesting significant difference between the children and adults in the study group was that children were apparently living in communities that had many fewer support services available than did the communities in which the adults were living ($p = .037$). It should be recalled that this measure included a count of alternative residential settings and a count of the institution's perception of the number of support services available in the community. A number of speculations are possible to explain this interesting difference: children are more likely than are adults to be released to natural families, and hence to communities that have developed fewer residential alternatives in general than have those to which adults are released; perhaps because of their release to natural homes, the extent to which their community has a variety of support services available is less likely to be a criterion for release than it is for adults who are more likely to be placed in a variety of types of group settings. Finally, it is interesting to speculate that there might be a relationship between the extent to which children are released to communities perceived by the institutions as not providing as much support, and the fact that institutions releasing children seem to be more inclined to provide continued support themselves in the community. Indeed, although there was not a significant difference between the children and the adults ($p = .325$), there seemed to be a definite tendency for children to be in communities in which a higher proportion of services provided to persons living in the community received those services from the institution as opposed to community providers. Similarly, children were more likely than adults ($p = .102$) to be living in communities that generally provided fewer services to both the clients and their families than did the communities in which the adults were living.

5. Differences in Community Experiences: Children were significantly less active than adults ($p = .002$) in terms of the composite score that included both day and spare time activities. Not surprisingly, children were also significantly more likely to live in more restricted residential setups

than were adults ($p < .001$). Confirming, perhaps, the notion that children are easier to place was that adults had significantly more problems overall than did children ($p = .003$). Indeed, adults were more likely than were children to have unmet service and training needs ($p = .018$). Although the difference was not significant ($p = .291$), there was a slight trend towards greater likelihood that adults would return to the institution than would children. All these community experience differences seem to indicate that children are perceived as doing less, but also needing less than adults.

3.2 Differences According to Level of Retardation

1. Differences in Individual Characteristics: Not surprisingly, the severely and profoundly retarded members of the study group scored significantly lower than did the mildly and moderately retarded individuals on Part I of the Adaptive Behavior Scale. No significant difference was found, however, on Part II of the ABS, although there appeared to be a slight tendency for the number of behavior problems to increase as the severity of retardation decreased (i.e., mildly retarded individuals were more likely than severely and profoundly retarded individuals to have behavior problems).

As was indicated above, the severely and profoundly retarded members of the study group were significantly ($p = .002$) younger than were the mildly and moderately retarded individuals. No difference was observed in terms of the distribution by sex of the three levels of retardation.

2. Differences in Institutional Experiences: Significant differences appeared among the study group members categorized by level of retardation on two aspects of institutional experience: spare time activities and day programs. Mildly retarded individuals had a higher frequency of participation in spare time activities while institutionalized than did the more retarded individuals.

Interestingly, perhaps because of the relationship between age and level of retardation, no differences were found among study group members in terms of length of institutionalization or age of first admission to the institution by level of retardation. Significant differences existed among all three levels of retardation with respect to the total number of day programs in which clients participated: the higher the functional level, the more the activities ($p < .001$). (Mildly retarded persons participated in an average of 1.1404 programs, moderately retarded individuals in an average of .8540 programs, and severely/profoundly retarded in .6415 programs.)

3. Differences in Institutional Characteristics: Of the institutional variables examined, the one on which the study group members differed most strongly by level of retardation was in the intensity of programming and per capita expenditures of the institutions from which study group members were released. In this case, mildly retarded individuals were released from institutions that were providing significantly more than were institutions releasing moderately retarded people, but significantly less than were institutions releasing profoundly retarded individuals. Thus, moderately retarded individuals were released from institutions that had the least programming available and the lowest per capita expenditures, while profoundly retarded persons were released from those institutions spending the most. This is an interesting finding, but one difficult to interpret. Perhaps it means that to increase the number of severely and profoundly retarded individuals placed in the community requires a greater investment by the institution. Another possibility is that as the institutions release their more mildly retarded individuals and thus reduce their overall populations, the average per capita expenditures and the programming available to the more retarded residents increases.

Although it was not significant at the required .05 level, there was a strong difference approaching statistical significance ($p = .086$) among the three groups in terms of family satisfaction with pre-release training. The more retarded the individual, the more likely the family was to be dissatisfied with the pre-release training received.

There were no other significant differences among the study group members in terms of institutional characteristics.

4. Differences in Community Characteristics: There were no significant differences among study group members in terms of the characteristics of the communities in which individuals at different levels of retardation were living. However, as with some of the institutional characteristics, there seemed to be some trend indicating that the community characteristics were most similar for the mildly retarded and the severely and profoundly retarded, and different for the moderately retarded individuals. In general it appeared that moderately retarded individuals were more likely to be living in communities that had the most available--from community as well as from institutional sources.

5. Differences in Community Experiences: There were important differences among study group members on all aspects of community experience measured. The strongest difference ($p < .001$) was in terms of the number of problems and the restrictiveness of residential settings. Mildly retarded individuals were more likely to have the fewest problems. Severely and profoundly retarded people were, not surprisingly, living in the most restrictive residential settings. The mildly retarded study group members, however, were most likely to have unmet needs ($p = .001$). There was a difference between the study group members in terms of activity level ($p = .250$), which indicated that the severely and profoundly retarded individuals were less active overall than were the less retarded individuals. There was a definite trend ($p = .102$) towards having the individuals who were less retarded be more likely to return to the institution than were the more retarded individuals.

Thus, although mildly retarded people had fewer problems, they also were more likely to be perceived as needing services and training that was not available and were somewhat less likely to remain in the community.

4.0 CORRELATIONS AMONG THE FINAL VARIABLES

A correlation was considered "strong" for this analysis if it was .25 or above. Using this criterion, there were quite a few variables that were "strongly" correlated with each other among the final set of variables, as well as some relatively small correlations that were unexpected.

4.1 Correlations within Groups

1. Correlations among Individual Characteristics: Using the criterion of .25, there were no strong correlations among the five individual characteristics. The correlation between level of retardation and score on Part I of the ABS, for example, was quite weak ($r = .1327$).

2. Correlations among Institutional Experience Variables: No strong correlations emerged among institutional experiences.

3. Correlations among Institutional Characteristics: The only strong correlation among institutional characteristics that emerged was between the extent to which the institution assumed responsibility for a released client in the community and the overall intensity of care provided in the institution ($r = .284$). The direction of this correlation indicated that the higher the intensity of services and expenditures within the institution, the lower the responsibility assumed by the institution for placements in the community. Perhaps this reflects a trade-off in the allocation of institutional resources: they can either be put into programming for individuals while they are in the institution, or they can be put into community support. A more optimistic conclusion might be that the intensive services within the institution paid off in the sense that residents released from high-cost institutions were better prepared and required less attention once they were in the community.

4. Correlations among Community Characteristics: Not surprisingly, there was a strong correlation between the variable measuring the amount of services provided to clients and their families and the availability of services and residential options in the community ($r = .4845$). Since these two measures had very different sources for the information, it would seem that the measures used to determine the degree of community support overall has a fair degree of validity.

5. Correlations among Community Experience Variables: The final outcome measures of different aspects of community experience were strongly related to each other but not so strongly as to indicate that there is a single measure of community "adjustment" derivable from the components used in this study. The total activity level of the individual mentally retarded person was correlated strongly with the extent of unmet need ($r = .2955$), with the direction of the correlation indicating that individuals who were more active overall, tended to have fewer unmet needs. The more active members of the study group were also less likely to return to the institution ($r = .2749$). Individuals with more problems were likely to have fewer unmet needs ($r = .4361$). This rather surprising relationship is probably an artifact of the measure used to determine "unmet need." This variable gave the individual a low score if services and training were not needed at all, a medium one if services and training were used, and a high score if they were needed but not used. An individual who had many problems might have been perceived as not being ready (i.e. not "needing") to use various types of training and services. Thus, s/he could well receive a lower score on this variable than the person, who because of fewer problems, used more services and training. Problems were also highly correlated with the restrictiveness of the residential setting ($r = .4224$), indicating that people with more problems lived in more restricted settings. The direction of causality, however, is not determinable from these data.

4.2 Correlations among the Groups of Variables

Correlations among the various "predictor" variables are reported in the following sections.

1. Correlations between Individual Characteristics and Other Variables:

The only variable with which performance on Part I of the Adaptive Behavior Scale was strongly correlated was the frequency of spare time activities while institutionalized ($r = .2779$), and the degree of independence in the community ($r = .3374$). The higher the functional level of study group members, the more spare time activities in which they were likely to participate while institutionalized ($r = .2628$), the more day programs they participated while institutionalized ($r = .2968$), and the more independent they were in the community ($r = .3009$).

Age was strongly correlated with the total length of time institutionalized ($r = .4444$), with older people (not surprisingly) spending more

time institutionalized than younger people. Immediately prior to release, older people participated in more day programs ($r = .2432$).

The correlation results correspond with the ANOVA results on age and level of retardation.

The sex of the individual was not found to be correlated with any other final variables.

2. Correlations between Institutional Experience and Other Variables:

The frequency of participating in spare time activities while institutionalized was strongly related to the number of day programs while institutionalized ($r = .3300$), with individuals participating more frequently in spare time activities also participating in more day programs prior to release. Frequency of participation in spare time activities while institutionalized was also strongly correlated with families' satisfaction with institutional pre-release preparation ($r = .2653$). Not surprisingly, families that perceived clients as having participated frequently in spare time activities were more satisfied with pre-release preparation.

The length of time that an individual was institutionalized was strongly correlated with the overall intensity of training and expenditures in the releasing institution ($r = .2752$), with clients who were institutionalized for longer periods of time being served in institutions with a lower overall intensity measure. This is an interesting finding: institutions spending more money overall and providing more services tend to release clients who have been living there for shorter periods of time. This does not mean that these institutions tend to keep their residents for shorter periods of time, but only that those whom they actually release have lived in the institution for less time. The length of time individuals were institutionalized is also strongly related to the extent to which services received by clients and families in the community are provided by the institution as opposed to community providers ($r = .4139$). The individuals who had remained in the institution for a shorter period of time tended to live in communities in which the institutions provided a higher proportion of the services received in the community. In sum, it seems that institutions that release clients after shorter stays tend to provide more, both in the institution and in the community. Individuals institutionalized longer probably because they were older, tended to be more independent in the community.

The length of time institutionalized was also strongly correlated with the length of time a periodic review policy had been in effect ($r = .2779$), with the longer the periodic review had been in effect the shorter length of time institutionalized. If the direction of causality can be assumed from the temporal order of the variables, this is an important finding in that it indicates that presence of a periodic review policy is directly related to the length of time that people spend in institutions.

The age at which the individual was first admitted to the institution was also related to the overall intensity of institutionalized programming ($r = .2922$), with persons who were admitted when they were older being released from institutions that had a higher level of intensity of programming. Perhaps this is because institutions in general seem to have more programs for adults that could specifically be labeled "pre-release" programs than they had for children -- and the age of first admission is highly related to the age of the individual at the time of the interview.

In sum, the experiences that the individuals had in the institution are strongly related to characteristics of that institution.

3. Correlations between Institutional Characteristics and Other Variables: In addition to being strongly related with length of institutionalization, the length of time a periodic review policy has been in effect in the releasing institution is strongly related to the amount of support provided the clients in the community. On the one hand, the longer the periodic review policy has been in effect, the more support the institution provides to clients living in the community and to their families ($r = .5910$). On the other hand, the longer a periodic review has been in effect, the fewer the support services available in the community as measured by alternative residential placements and the institution's perception of the number of services available in the community ($r = .2451$), and as measured by the actual amount of services provided clients and their families ($r = .5308$). It is difficult to interpret this finding, unless it reflects resource allocations within the state's mental retardation system: as a periodic review policy is implemented more resources are required in the institution, leaving fewer for the community.

In this light, there is a strong negative correlation between the satisfaction that a family expresses with the pre-release preparation received by the client and the amount of support available in the community ($r = .2578$). This is perhaps yet another indication that there is a trade-off between the provision of institutional and community services.

The more the institution perceives itself as having a role in supporting clients and their families upon release, the greater the proportion of services to clients and families in the community that are provided from the institution rather than community sources ($r = .3475$). This is interesting since the information about the institutional role was obtained from the institutions, while the information on the proportion of services and training provided by the institution to clients and families in the community was obtained from the families. The independence of the scores of information would indicate that these two measures of the degree of institutional support have a reasonable degree of validity.

4.3 Correlations between Community Experiences (Outcome Variables) and Other Variables: Community experiences were strongly related to a number of individual experiences. The score received on Part I of the ABS, functional level, was highly related to independence in the community ($r = .3374$). Surprisingly, the score of Part II, negative behavior, was not correlated with any outcome measures. The age of the individual was also related to independence ($r = .3158$) as was level of retardation ($r = .3009$). Level of retardation was also correlated with total number of problems, with individuals with a lower IQ having fewer problems. Sex was not correlated with any community experience variables.

Institutional experiences were generally not correlated with community experiences, with the exception of independence in the community. This variable was strongly correlated with length of institutionalization ($r = .2637$) and participation in day programs prior to release ($r = .2364$). However, both of these variables were highly related to the age of the client ($r = .4444$ and $.2432$ respectively), thus perhaps accounting for much of the relationship.

Institutional characteristics were not highly correlated with community experiences.

There were, however, strong correlations between community characteristics and community experiences. Specifically, the amount of support available in the community as measured by residential options and institutions' perceptions of the amount of services available was strongly correlated with the overall activity level of the mentally retarded person ($r = .443$), and with the total amount of unmet need for services and training for the client in the community ($r = .4908$). Overall, the more that exists in the community, the more active the clients are, the fewer their restrictions, and the lower their unmet need.

A similar but less strong relationship was seen between the total amount of services and training provided clients and their families as measured by services actually used and those needed and perceived as available by families, and the overall activity level of the client ($r = .3347$). A strong correlation ($r = .2740$) between this variable and independence of clients was also found.

The extent to which the institution is the provider of services to clients and their families while in the community is strongly related to the independence of the client ($r = .3109$), and, interestingly, to returning to the institution ($r = .2562$). The institutions tend to provide a higher proportion of services and training to clients and families of individuals living in more restrictive settings and to individuals who have returned to the institution. It is difficult to interpret this finding, since the direction of the association is not unknown: it is that when individuals are less independent, they simultaneously have difficulty obtaining needed services from community providers and are also more likely to return to the institution because of their lack of independence, or is it that clients who receive most of the support from the institution rather than from the community are less likely to become integrated into the community and thus are more likely to return to the institution.

Congruent with the basic philosophy underlying deinstitutionalization, the degree of support provided to clients and their families in the community is strongly correlated with returning to the institution ($r = .2723$), with individuals being less likely to return to the institution when more services and training are provided to clients and their families.

There were only two variables that were strongly correlated with returning to the institution, and both had to do with the services provided to clients and their families: the overall amount provided in the community, and the proportion of this total amount that was provided by the institution. In general, it seems that persons who stay in the community are living in communities where more services are actually being provided, and where a larger proportion of these services are provided by community rather than institutional sources.

5.0 RESULTS OF THE STEP-WISE REGRESSIONS

Two major sets of regressions were performed: (1) one regression was performed using returning to the institution/remaining in the community as the single outcome variable, against which all the other final variables were used as potential predictors; (2) regressions were performed using the other four community experience variables as the outcome measures, and using the remaining seventeen predictor variables in the equations. Thus, these four community experience variables (problems, unmet need, independence, and level of activity) were used both as predictor variables against returning to the institution/remaining in the community and as outcome measures in their own right. The step-wise regression technique used was not forced in any way: variables were entered into the equation in the order in which they accounted for the greatest amount of additional variance in the outcome measures.

The variables are reported in this order. The percent of the observed variance of the outcome variable for which each predictor variable accounts is listed. In addition, the significance of the contribution by each additional predictor variable is reported. A cutoff of approximately .05 was used to determine which predictor variables would be included in the final equation. Since the precise weighting of each variable changes as variables are added, some of the final variables included in the equation are not significant at the .05 level. They are, nonetheless retained and reported. From the perspective of this report the most important aspect of the regressions is a listing of the final set of variables that seem to be predicting the outcome measure in question. The precise weightings of the variables are not reported.

The results of the step-wise regressions are reported in the following table.

5.1 Returning to the Institution/Remaining in the Community

The final equation used to predict whether or not a mentally retarded person would remain in the community contained ten predictor variables and accounted for over 20 percent of the observed variance. The first two predictor variables (accounting for about 11 percent of the total variance) were other measures of community experience: total activity level (the more activities the less likely to return to the institution), and total problems (the more problems the more likely to return to the institution).

Summary Table of Results of the Step-wise Regressions

Outcomes	Predictors	Step #	% of Variance	Significance
1. Remaining in the Community	Higher overall activity level	1	7.556%	P < .001
	Fewer problems	2	4.1	P < .001
	Smaller proportion of all services and training provided by the institution	3	3.0	P < .001
	Younger age at first admis- sion	4	1.8	P = .029
	More institutional prepar- ation of community	5	1.3	P = .037
	More institutional pro- gramming intensity	6	1.0	P = .051
	More retarded clients	7	0.8	P = .039
	Younger clients	8	0.5	P = .034
	More participation in day programs prior to release	9	0.8	P = .054
	More support services available in the community	10	0.6	P = .088
	OVERALL EQUATION		21.444	P < .001
2. Overall Activity Level	More support services available	1	11.203	P < .001
	More services and training provided in the community	2	5.1	P < .001
	More spare time activities while institutionalized	3	1.1	P = .046
	Older clients	4	0.8	P = .053
	OVERALL EQUATION		18.267	P < .001
3. Fewer Problems	Less retarded clients	1	4.565	P < .001
	More support services available in the com- munity	2	1.5	P = .009
	Participated in more day programs prior to release	3	1.2	P = .046
	Fewer undesirable behaviors measured on ABS Part II	4	1.0	P = .032
	More services and training provided in the community	5	0.7	P = .084
	Younger clients	6	0.7	P = .092
	OVERALL EQUATION		9.559	P < .001

Outcomes	Predictors	Step #	% of Variance	Significance
4. More independence in residential setting	Older clients	1	9.975%	P < .001
	More services and training provided in the community	2	6.6	P < .001
	Less retarded clients	3	5.8	P < .001
	Smaller proportion of all services and training provided by the institu- tion	4	5.5	P < .001
	Higher functional level measured on ABS Part I	5	4.8	P < .001
	More support services available in the community	6	1.1	P = .014
	Participated in more day programs prior to release	7	.5	P = .078
	OVERALL EQUATION		34.293	P < .001
5. Less unmet need	More services and training provided in the community	1	9.523	P < .001
	More retarded clients	2	2.7	P = .002
	Smaller proportion of all services and train- ing provided by the institution	3	2.4	P < .001
	Younger clients	4	1.4	P = .003
	Older at age of first admission to institution	5	1.4	P = .011
	OVERALL EQUATION		17.399	P < .001

Of the remaining variables, three were institutional characteristics or were related to the role that the institution plays in providing continued support to released clients in the community. Specifically, the more the institution does prior to release, in terms of the intensity of programming provided to the mentally retarded person, the more the institution does to prepare the community for the resident, but the less the institution does once the client is in the community, in terms of the proportion of services provided, the more likely it is that the mentally retarded person will remain in the community after release.

Three other variables dealt with individual characteristics, clients who were older at the time of the interview, older when they were admitted to the institution, and less retarded, were more likely to return to the institution than were younger more retarded individuals. This fits with some of the other findings reported above that seems to indicate that children were more retarded yet were easier to retain in the community than were adults.

Those clients who participated in more programs were more likely to remain in the community, as were those living in communities which had more support services available.

5.2 Total Activity Level

The final equation used to predict overall activity level of the mentally retarded person in the community contained four predictor variables and accounted for about eighteen percent of the total observed variance. The first two predictor variables in the equation (accounting for about sixteen percent of the variance observed) were both community characteristics related to the amount of service provided and available. Not surprisingly, the more the mentally retarded person does, both in terms of day activities and in spare time activities.

The other two predictors indicated that the more a person does in the institution in terms of spare time activities, and the older the clients, the more s/he is likely to do once released to the community.

5.3 Problems

The final equation used to predict the number and intensity of the problems which the mentally retarded person had in the community contained seven predictor variables and accounted for about ten percent of the observed

variance. Surprisingly, the strongest single predictor (accounting for about seven percent of the variance) was the level of retardation of the individual: the more retarded, the more problems the individual had. Of the five remaining variables two others were individual characteristics and three were characteristics of the individual's institutional experience. Specifically, mentally retarded persons who had higher scores on Part II of the ABS, (maladaptive behaviors) and individuals who were younger were reported to be having more problems in the community. On the other hand, persons who were older when first admitted to the institution were more likely to have problems upon returning to the community than were those who were younger--perhaps deriving from the original reason for the institutional placement which was not reported for this study. The individuals with more prerelease training had fewer problems in the community. An important finding was that if individuals lived in communities that had fewer supports available and fewer services and training actually provided, they were likely to have problems.

In sum, it seems that the number of problems a family perceives a mentally retarded person as having derives from characteristics which the resident enters the community with (both in terms of demographic and institution experience characteristics) and that they live in communities offering less support.

5.4 Independence in the Living Setting

The final equation used to predict the amount of independence that the mentally retarded person had in his or her residential setting contained seven variables and accounted for over 34 percent of the observed variance.

Of the seven variables, three measured different aspects of overall functional level: mentally retarded persons whose functional level as measured by Part I of the ABS was higher, who were less retarded, and who were older were more likely to be independent. This finding is not, then, surprising. What is extremely interesting is that the greater the proportion of services and training used by mentally retarded persons and their families in the community that is provided by the institution, the less independent is the mentally retarded person. It is difficult here to determine the direction of this relationship: do individuals who are more dependent need

to receive more from the institution, or does more support from the institution somehow result in less independence on the part of the mentally retarded person? It is not possible from the data to answer this important question.

It is, however, interesting to note that one variable which was related to the degree of independence was the amount of community support available as measured by the institution's perception and the availability of alternative living settings. It might well be, then, that the degree of independence that an individual mentally retarded person is able to achieve is derived not only from his or her own inherent abilities, but from the availability in the community of options for obtaining greater support and of having available settings that can be matched reasonably carefully with the ability of an individual to live independently. Thus, in a community with few residential options, it might well be that all persons must live under similar constraints regardless of ability, while in a community with more options it is possible to establish settings that have at different degrees of structure, depending upon an individual's ability to cope.

Finally, the more individuals participated in day programs while institutionalized, the more independent they were once released.

5.5 Unmet Need

The final equation used to predict the amount of "unmet need" that the study group members had contained five predictor variables and accounted for over eighteen percent of the observed variance. As might be expected, the first variables indicated that the more services and training were provided in the community the lower the unmet need. Not so obvious, however, was the finding that the greater the proportion of these services that was provided by the institution, the greater the unmet need. Once again, a pattern emerges that depicts the institution as the fall-back provider, stepping in to supplement inadequate services within the community itself.

All three remaining variables were demographic characteristics of the individuals. Individuals who were younger when first admitted to the institution, were more likely to have unmet needs when they were released to the community, who were less retarded and were older at the time of the interview were also more likely to have unmet needs. These findings correspond to ones previously reported: it seems that mildly retarded adults are

percieved as needing more than they are currently receiving in the community. It should be recalled that, built into the measure of "unmet need," is the perception of the respondent about whether or not the individual needs a particular type of training or service. Thus, it is possible that respondents feel that younger and more retarded persons would not benefit from particular services or training and therefore do not "need" them.

The findings have been reported above primarily in terms of the outcome variables: which predictor variables were related to each outcome variable. The results will be discussed across outcome variables in terms of each category of each predictor variable.

5.6 Individual Characteristics

In general, individual characteristics were not the strongest predictors of the different aspects of community adjustment examined. However, they did show up as among the strong predictors in every case. The two characteristics that were strongest were level of retardation and age. It should be recalled that for the study group these two variables were also highly related to each other: younger persons were also more retarded. In general, it was found that younger more retarded individuals were more likely to remain in the community and were precieved as having fewer unmet needs. However, older less retarded clients were more active and more independent. Younger less retarded clients had the fewest problems.

Functional level was only found to be related strongly to independence not a surprising finding. Undesirable behaviors, also not surprisingly, was most strongly related to having problems in the community. The sex of the clients was not found to be strongly related to any of the outcome measures.

5.7 Institutional Experiences

Institutional experiences did effect post-institutional experiences, according to the findings reported above. Specifically, it was found that the more the client did in the institution, the more s/he is likely to do when in the community. Also, clients who received more training while institutionalized had fewer problems in the community and had fewer unmet needs in the community.

The other institutional experience variable that was a strong predictor of a number of outcomes was age at first admission. It was found that individuals who were younger when first admitted to the institution tended to remain in the community (perhaps because they were also more likely to be children), but once in the community they were more likely to have unmet needs.

The total length of time institutionalized did not emerge as a strong predictor of any of the outcome measures, perhaps being accounted for largely by the age of the client.

5.8 Institutional Characteristics

Institutional characteristics showed up surprisingly strongly as predictors of individual's performance in the community. It was found overall that the more the institution did for clients and the community prior to release into the community, the better individuals seemed to fare. Specifically, the composite variable measuring "institutional programming intensity" was a strong predictor of remaining in the community, and of clients' overall activity level while in the community. The extent to which the institution prepared the community for mentally retarded persons was related to whether or not persons remained in the community after release.

In addition, although it was considered a characteristic of the actual services received by persons in the community, the extent to which the institution was the provider of services to clients and their families was an extremely important variable. The larger the role of the institution in providing services, the more likely it is that mentally retarded persons will return to the institution, that they will be living in less independent residential settings, and that they will have unmet needs for services and training. As has been discussed above, the direction of these relationships is unclear: it certainly does not seem that a conclusion can be drawn that the more the institution does the worse it is for the mentally retarded person in the community. Rather, it would seem that the institution provides a fall-back for mentally retarded persons who live in communities that do not themselves have adequate support services and that this fall-back role is insufficient to retain the individual in the community satisfactorily.

5.9 Community Characteristics

It is clear from the results of the analysis that the extent to which various types of supports are available and actually provided to mentally retarded persons living in the community, the better is their "adjustment." The two variables measuring different aspects of community support consistently demonstrated that the greater the support, the more likely it is that a mentally retarded person will remain in the community, will be more active, will have fewer problems, will be living more independently, and will have fewer unmet needs.

5.10 Community Experiences

The community experience variables were used as predictors of returning to the institution versus remaining in the community. As was described above, the two aspects of the community experience that were most strongly related to remaining in the community were more activities and fewer problems. Independence and unmet needs were not related to returning to the institution.

6.0 SUMMARY

The data reported in this volume point in a number of important directions for the future of deinstitutionalization efforts in this country. The key findings are summarized in this section. It is crucial to realize, however, that there are no clear determinants of "successful" adjustment, nor are there clear measures of "success." Rather, the processes being observed are extremely complex. This must be kept in mind in reviewing the specific findings summarized below.

1. The level of retardation of a mentally retarded person will have a direct impact on that person's "community adjustment."

Specifically, more retarded individuals will be less likely to return to the institution, to be perceived as having unmet needs than less retarded persons who will be more active and be living more independently in the community.

This finding strongly suggests that level of retardation per se should not be used as a determinant of whether or not a person can "make it" in the community. Indeed, persons of all levels of retardation can make it, and in some ways, perhaps because expectations are lower, more severely retarded persons might actually have less difficulty than less retarded persons.

2. The age of the mentally retarded person will have a direct impact on that person's adjustment to the community.

Specifically, the younger individuals will be less likely to return to the institution, and will be perceived as having fewer problems and unmet needs than adults who will be living more independently in the community than children.

This finding suggests that while people of all ages can and do "make it" in the community, that children are perceived as being somewhat easier to accomodate by the community than are adults.

(It should be noted that for our study group level of retardation and age were strongly related, with younger clients being more retarded. However, both age and level of retardation were found to have strong independent impacts on the various outcome measures used.)

3. The extent to which a mentally retarded person is involved in many activities in the institution prior to release has a direct impact on post-institutional adjustment.

Specifically, individuals who participated in more spare time and training activities were more likely to remain in the community to be more active upon release, to have fewer problems, and to have more independence in their living setting than study group members receiving less institutional preparation.

This finding is corroborated by the related finding that persons released from institutions which had more training available and which spent more money overall were less likely to return to the institution.

These findings strongly suggest that while individuals can and do "make it" without much prerelease preparation, that they are more likely to be successful than individuals without as much preparation.

4. The roles which institutions play in providing support to the community and to released clients has a strong impact on the adjustment which mentally retarded persons make in the community.

Specifically, mentally retarded persons released from institutions which prepare the community prior to a client's release do better, and persons released from institutions which provide a large proportion of services received in the community do less well. Mentally retarded persons released from institutions which provide support to the community prior to release of clients are more likely to remain in the community than are clients released from institutions providing less preparation. Conversely, mentally retarded people living in communities where a large proportion of services and training are provided by the institution are more likely to return to the institution, are living in less independent settings, and have more unmet needs.

These findings, combined with the previous finding, strongly suggest that the more the institution does prior to release the better off the client is, but conversely, the less the institution does after release the better the mentally retarded person does in the community.

5. The amount of support available in the community for mentally retarded people and their families directly affects other community adjustment.

Specifically, mentally retarded persons living in communities which have a wide range of services, training and residential options available do better than mentally retarded people living in less supported communities. The more support available in the community, the more likely is the mentally retarded person to remain in the community, to be more active, to have fewer problems, to have more independence, and to have fewer unmet needs.

These findings strongly suggest that if more community services are available, then mentally retarded persons will have better "adjustment" in the community.